

**BOTH
SIDES,
NOW**

2021 – 2022

END-OF-LIFE IN THE MALAY-MUSLIM COMMUNITY

**Mengukir
Harapan**

**RESEARCH
REPORT**

PREPARED
BY ARTSWOK
COLLABORATIVE
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Arts Workshops in 2022 facilitated by P7:ISMA with elders from Montfort Care - GoodLife! Bedok

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Lepaskan Sesalan (Release Your Regrets) public engagement event 2022 at Heartbeat@Bedok

Introduction

Since 2013, *Both Sides, Now* (BSN) has emphasised public engagement and dialogue by using end-of-life matters as a stimulus to build healthy, connected communities that contribute towards living and leaving well. Past initiatives have been shown to be effective in enhancing awareness of participants towards end-of-life issues and resonates with Singaporeans across various demographics as well as socio-economic backgrounds. However, participation in and content of such programmes tend to appeal more to attendees from the dominant ethnic Chinese community, creating a need to develop and tailor culturally competent programmes that would be more relevant and familiar to minority ethnic groups. This study thus represents a collaborative effort between BSN (creative team) and Age Matters (research team) to develop culturally competent arts-based approaches to engage the Malay-Muslim community on end-of-life and advanced care planning issues. This study engages a participatory community-led design to understand pertinent issues and contexts, leading to the development of culturally competent approaches to engage Malay-Muslim members in end-of-life issues. We do so by analysing interview data of key resource persons and observations during Community Engagement Workshop (CEW) sessions.

Organisation of CEW Sessions and Demographic Profile

GROUP	AGE	MALE (~%)	FEMALE (~%)
CEW #1 (17–21)	18–21 : 6	1 (20%)	5 (80%)
CEW #2 (22–30)	22–29 : 10	3 (30%)	7 (70%)
CEW #3 and #4 (31–39)	31–39 : 10	3 (30%)	7 (70%)
CEW #5 (First-born/only child)	18–30 : 6 31–40 : 2 41–50 : 1	4 (45%)	5 (55%)
CEW #6 (Single caregivers)	30–40 : 2 41–50 : 2	3 (75%)	1 (25%)
CEW #7 (55 and above)	55–59 : 5 60–69 : 2 70+ : 1	3 (35%)	5 (65%)

Table 1.
Demographic
Distribution of
CEWs Based
on Age
and Gender

Between 13 March and 10 April 2021 BSN organised and conducted a total of 7 Community Engagement Workshops with 47 Malay-Muslim members who responded to an online registration form for the CEWs. A total of 86 people signed up for the workshops but only 47 participants attended. Given the uncertainties imposed by the Covid-19 pandemic and since the workshop activities cannot be conducted through an online format, the teams decided to go ahead with the planned CEW sessions.

The creative team facilitated the CEW sessions using various devices: storytelling, word-listing, symbol-associations and group discussions to elicit meanings and cultural understandings from the participants with regards to the death and dying process, attitudes towards end-of-life issues as well as issues surrounding end-of-life. The research team attended all the sessions and took detailed observation notes.



A volunteer facilitating conversations with audience members during *Lepaskan Sesalan* (Release Your Regrets) public engagement event 2022 at Heartbeat@Bedok

The CEW sessions were held at two locations: Goodman Arts Centre and Aliwal Arts Centre depending on availability of venues. Sessions were conducted with safe management measures in place. Participants observed 1 metre distancing and masks were worn at all times.

CEWs were organised primarily based on age-bands as both the creative and research teams anticipated that concerns about and exposure to end-of-life issues may vary based on age. Other key determinants also included gender, birth hierarchy and caregiving status, as indicated in the formation of the CEWs.

Within the CEWs, men and women participated in mixed gender settings except for the oldest-age group because we anticipated that older Malay men and women may be more comfortable interacting and discussing with others of similar gender. CEW #3 (male) and #4 (female) were conducted on separate dates in anticipation of high volume of registered participants. However, there was high attrition in the CEW #3 (male) on the day itself.

Interviews with Key Resource Persons

PROFESSIONAL/EXPERT DOMAINS	TOTAL
Social work (palliative care, community care, MSW)	7
Lawyer	1
Age-care practitioner	1
Researcher (Malay studies/palliative care/ageing and health)	2
Nursing (hospice)	1
Interfaith advocate	1
Nursing home resident	1
Geriatrician	1
Healthcare administrator	1
	16

Table 2. Profile of Key Resource Persons

Prior to engaging Age Matters, BSN engaged a third-party evaluation company Just Cause to conduct interviews with individuals identified as “key resource persons” in the Malay-Muslim community. Resource persons are described as individuals with (i) cultural and/or (ii) professional expertise in domains related to health and ageing, palliative care, end-of-life needs, Malay studies and legal and Islamic knowledge.

Sixteen individuals were identified and described in the table above. The research team analysed interview transcripts and thematic findings which then triangulated with analysis from CEW observations. With the exception of two Chinese medical social workers, the resource persons interviewed all identified as members of the Malay-Muslim community and expressed familiarity with Malay culture and community practices.

Methodology



Research participants in discussion during a Community Engagement Workshop session

The research team utilised a three-pronged approach when collecting and processing data for the project. We began with participant observation during the CEWs – data from the seven sessions (refer to Annex A for the demographic breakdown of the sessions and the respective researcher present) were then coded and extensively discussed to generate the thematic linkages between the sessions which we describe in detail in *15 Thematic Linkages from Community Engagement Workshops*. Additionally, and when necessary, themes that are especially pertinent in a specific CEW session are signposted throughout the mind maps that are presented, and their descriptors. These thematic linkages were then triangulated with other sources of data that were collected prior to the commencement of the workshops, which consist of 1) resource person interviews conducted by the creative team and 2) the findings which were earlier generated and summarised by Just Cause. The outcome of this

triangulation is further drawn out and explicated in *Thematic Overview*.

Based on the conclusion of both *15 Thematic Linkages from Community Engagement Workshops* and *Thematic Overview*, we then went on to sketch archetypes in *6 Archetypes*, which are based both on the triangulated findings and also the six starting points for “readiness” to engage with end-of-life issues which Just Cause had earlier identified. Subsequently, we proceeded with *Programme Recommendations* where we provide recommendations that are tailored to both the research findings and also the presented archetypes, before finally ending off with *Proposed Programme Theory To Promote End-of-Life Engagement in The Malay-Muslim Community* where we lay out the contexts and mechanisms which will need to be considered in order to achieve the outcomes suggested in the programme recommendations. We finally end with *Annotated Resources and Further Reading*.



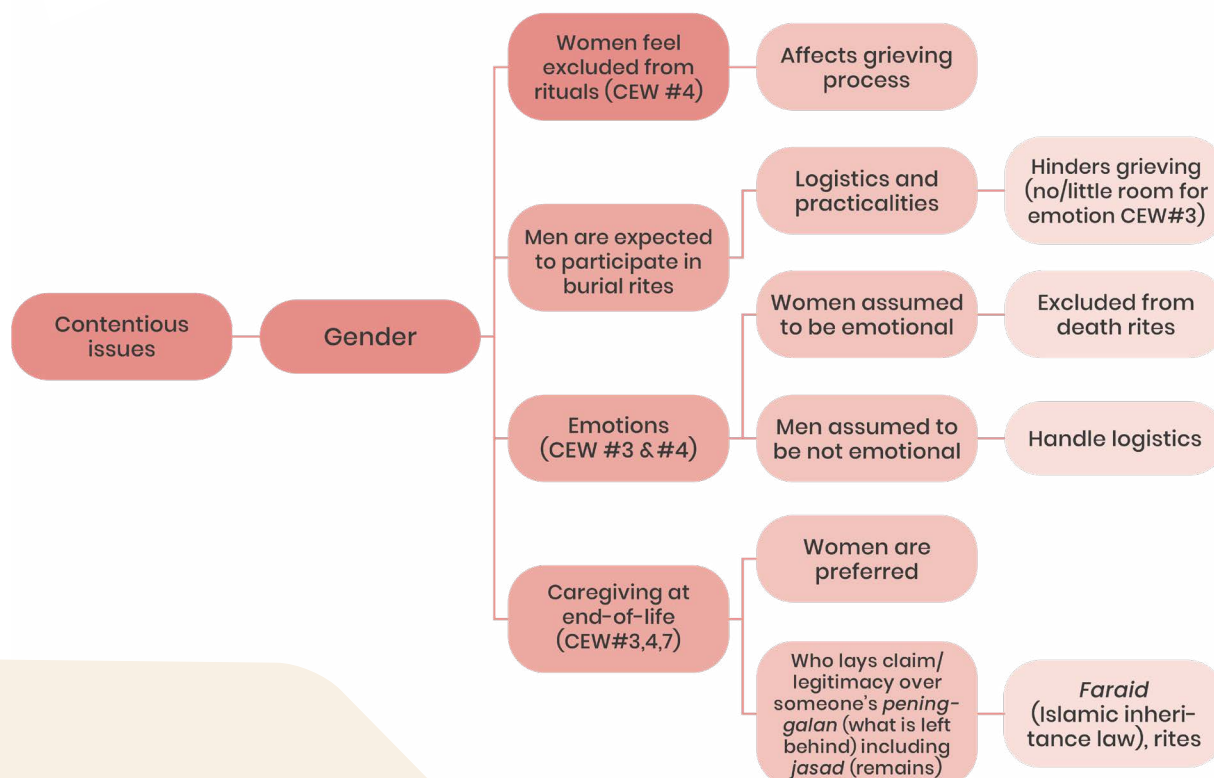
Artist Hasyimah Harith from P7:ISMA engaging with an elder from Montfort Care - GoodLife! Bedok during an Arts Workshop session

1

15 Thematic Linkages from Community Engagement Workshops

As part of the CEWs, we embarked on participant observation during the seven sessions to capture the sentiments and thoughts shared by participants, and the ways in which the participants responded to and engaged with the questions posed by the facilitators and the exercises which they participated in. These observations were recorded in the form of “observation notes”, which we coded in a software (NVivo12). We then discussed the coded observation notes as a team, and derived the thematic linkages based on the important points which were highlighted through the coded extracts. This discussion resulted in a total of 15 themes which we identified as particularly pertinent to the Malay community when grappling with issues surrounding end-of-life. These 15 themes will be presented in the form of mind maps below, with a description for each theme.

1 Contentious Issues: Gender

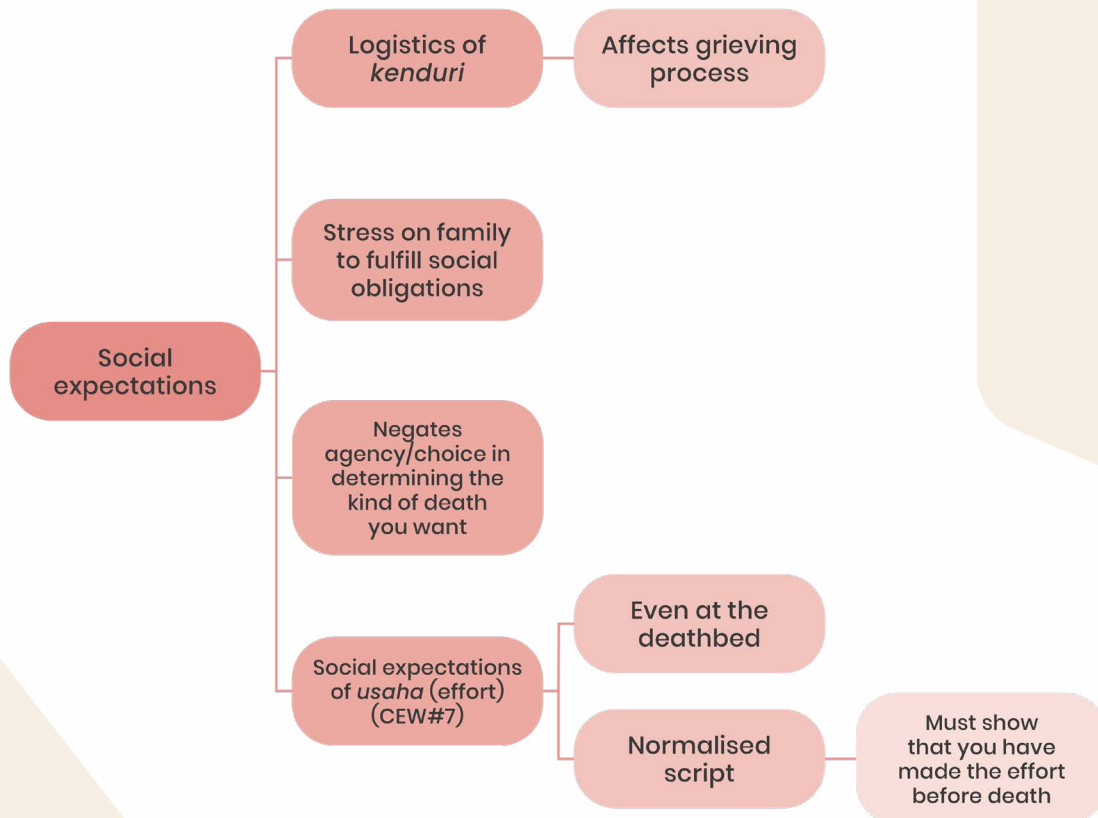


Contentious issues that were brought up by the participants dominated the sessions extensively, and upon further examination of the issues presented, we concluded that the majority of these issues stemmed from the root cause of gender; whether it was in the form of gendered expectations, gendered division of labour or issues that revolved around gender performativity in the community. These contentious issues revolving around gender are also grounded in structural understandings of gender in the Malay community, where the strict demarcation of roles is laid out according to the expectations that Malay bodies are deemed to inhabit. While individuals may not necessarily adhere to these roles strictly, they are still bound in various ways

to these rules, even in the process of negotiating around and breaking them.

The participants also relayed the ways in which they understand, negotiate, witness, or even come to terms with these contentious issues surrounding end-of-life vis-à-vis the lens of gender. They also elaborate at length on the ways in which many of these contentious issues manifest itself around gender or with gender as the root cause; such as in the ways women are excluded from rituals which was pertinent in CEW #4, the expectations on men to lead during burial rites – which might actually hinder the grieving process, and the impact of these gendered demarcations on the processing of emotions and also the caregiving process at the end-of-life.

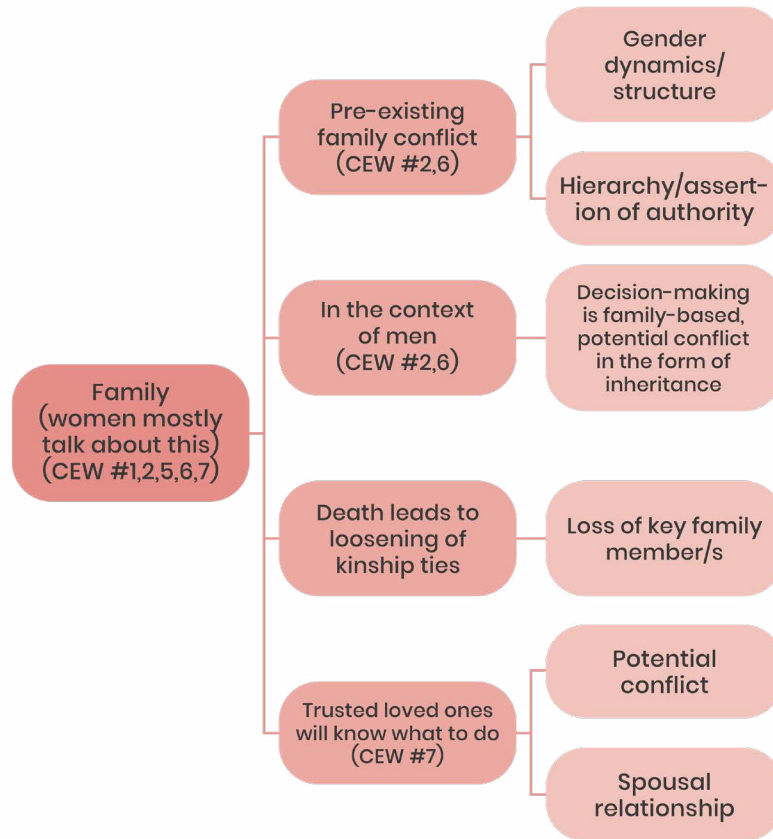
2 Social Expectations



Social expectations greatly impacted how the participants saw the end-of-life process, particularly with respect to rituals. Many participants spoke about how the logistics of the *kenduri* (which stands for a gathering held to commemorate the dead and usually consists of prayers read out and meals partook in a communal setting at the end) can either facilitate or hinder the grieving process depending on adherence to social expectations. Despite facing a loss, there is also pressure on the family to

fulfill social obligations, which might lead to the negation of choice or agency in the way that a person might intend for their death to be like. In CEW #7 particularly, the tension that played out between two male participants highlighted the social expectation of *usaha* or effort, which points towards the existence of a normalised script surrounding death, in which proof of effort made before surrendering to death is expected to be provided and accounted for in a perverse display of accountability.

3 Family

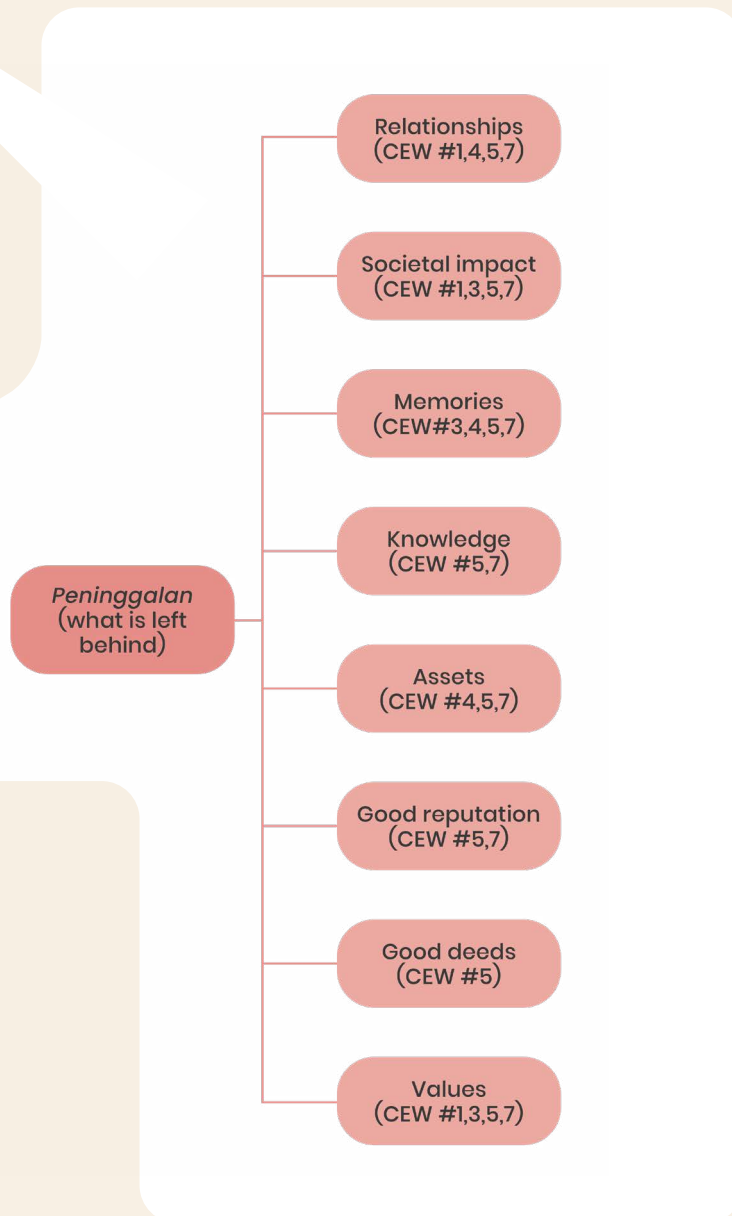


While male participants also mentioned family and/or family members during the CEW session, we found that it was the women who overwhelmingly brought up the issue of family or centered it in their discussions surrounding end-of-life issues. This is not surprising, especially in the context of the findings in Theme 1. Pre-existing family conflict was a dominant theme in both CEWs #2 and #6, particularly in the context of decision-making. Both gender dynamics and also the assertion of authority in the form of hierarchy greatly affected family relations, especially within the domain of inheritance.

On the other familial front, death could also potentially lead to the loosening of kinship ties when persons who were regarded as family

anchors were no longer around. In CEW #7, a heated discussion also occurred among the women in the group with regards to whether it was expedient to leave it up to their respective children who “will know what to do when we pass away”. While a participant mentioned that she placed complete trust in her children to deliver on what she would have wanted, the other women present questioned whether this was wise, or could in fact lead to more conflict in the future. The spousal relationship was also problematised by some of the participants, as they mentioned spouses who were either not ready or not willing to hear about what participants wanted for themselves at the end-of-life.

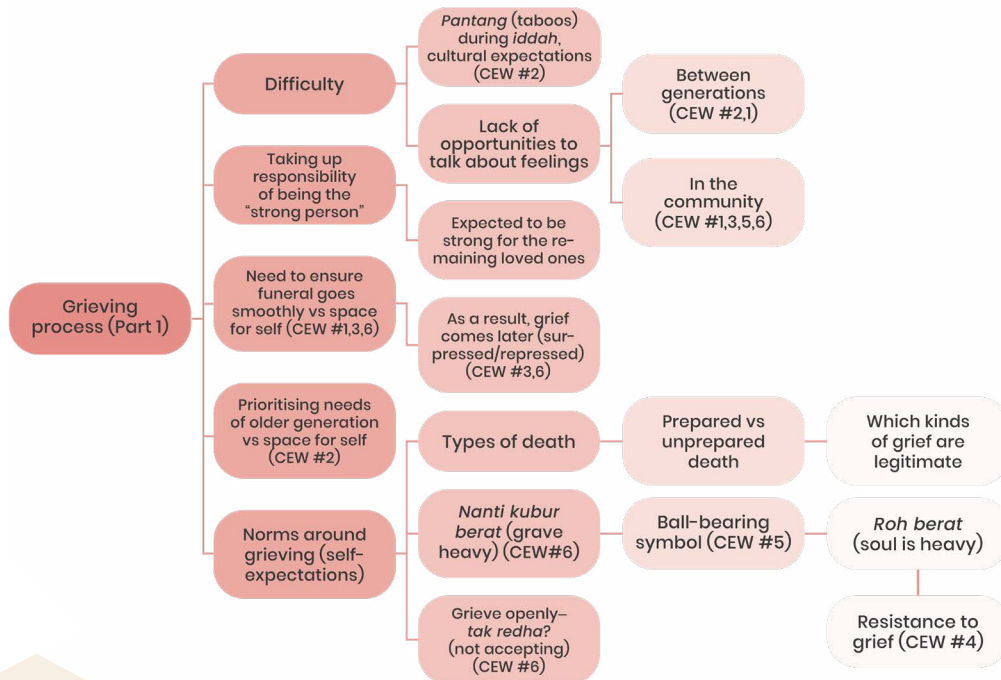
4 *Peninggalan* (What is left behind)



Based on an exercise conducted during the CEWs (prompted by the question posed by the facilitators on what the participants wanted to leave behind when they passed on), these were the dominant items referenced by the participants. It is noteworthy that while assets were mentioned, the majority of items identified

were non-tangible, and revolved around items that were more relational or relationship-based in nature, such as memories and values. This ties in with the Malay concept of *kenangan*, or things that one is regarded for even when a person is no longer physically present or in close proximity.

5 Grieving Process (Part 1)



Perhaps unsurprisingly for a series of workshops which revolved around death and dying, the grieving process formed a substantial bulk of the discussions. What was interesting though, are the nuances and depth which could be excavated from the discussions surrounding the grieving process. We chose to classify it as a process when synthesising the data, as we recognised that the participants often spoke about different stages of grief as a reference point when relaying their experience. In particular, many participants spoke about the difficulty of grieving, particularly when compounded with cultural and religious expectations such as the *iddah* (the 40-day period in which a wife is expected to be in seclusion upon a husband's death) in CEW #2, or the lack of avenues in which feelings could be discussed in the open. This gap was also observed between generations, as voiced out by the younger participants in CEW #1 and #2, and more widely, in the community, as elaborated by the

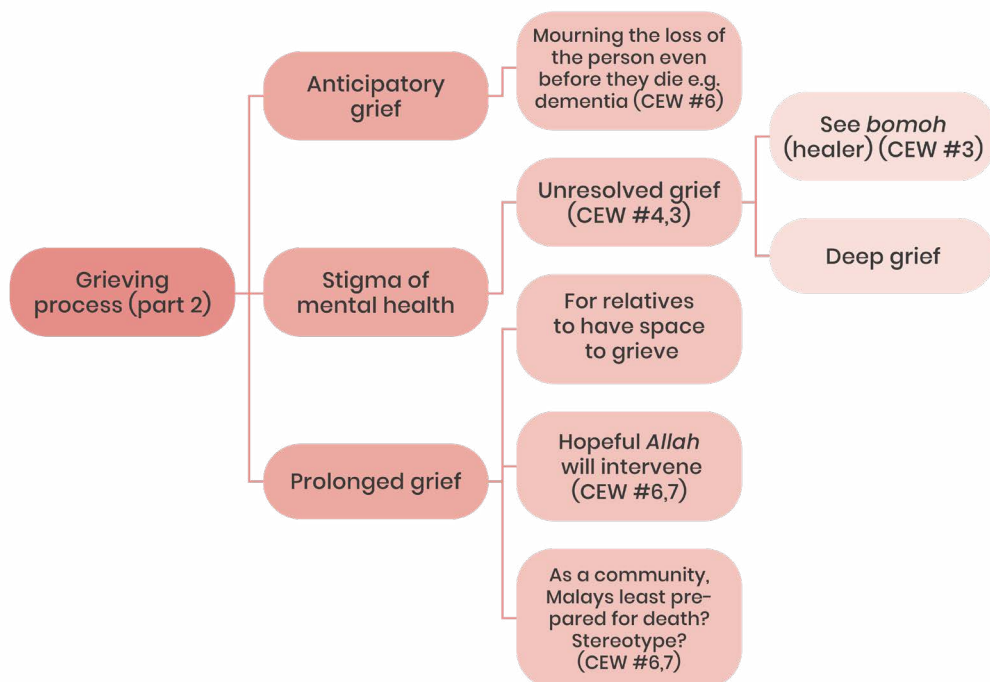
participants in CEW #1, 3, 5 and 6.

Participants also described having to take on the heavy mantle of being the strong person, particularly to ensure that funeral arrangements were taken care of as described in CEW #1, #3 and #6. Participants also resented the ways in which the emotional needs of the older generation often superseded their own grieving needs. Norms surrounding grieving also posed a hindrance in the grieving process, particularly in unexpected deaths, which served to delegitimise or suppress some forms of grief through social sanctions. Participants in CEW #6 spoke about how those who grieved openly were seen as not accepting of the death or fate especially when the griever is seen as unable to let go, causing it to be difficult for the departed to go as their soul is heavy. Grief is also metamorphosed as a ball-bearing for a participant in CEW #5, particularly when there is resistance to it according to participants from CEW #4.



Research participants at a Community Engagement Workshop session

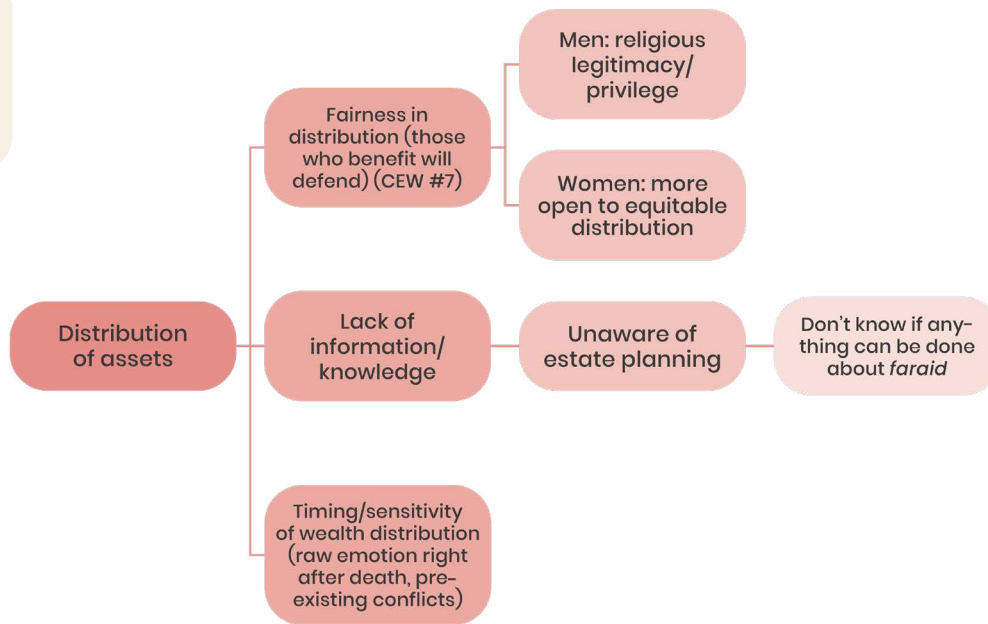
6 Grieving Process (Part 2)



The second part of the theme revolving around the grieving process primarily revolves around the idea of both anticipatory and prolonged grief, and the stigma around mental health issues. Anticipatory grief was particularly heartbreaking for participants in CEW #6 as it was a form of grief that had to be endured despite the loved one still being around. The idea of prolonged grief manifested itself through the stereotype held by some of the participants (particularly in CEW #6 and 7) of Malays being the least prepared community for death. This was compounded by the misplaced (?) hope that *Allah* (God) will

intervene, and finally the difficulty of holding space for others (in this instance, relatives due to the commonly extensive kinship network of the Malay community) while at the same time going through one's own grieving process. Finally, participants in CEW #3 and 4 discussed how the stigma surrounding mental health could actually lead to unresolved and even deep grief, with a health professional in CEW #3 bemoaning how some members of the community were more comfortable with seeing a *bomoh* or traditional healer than approach a mental health professional.

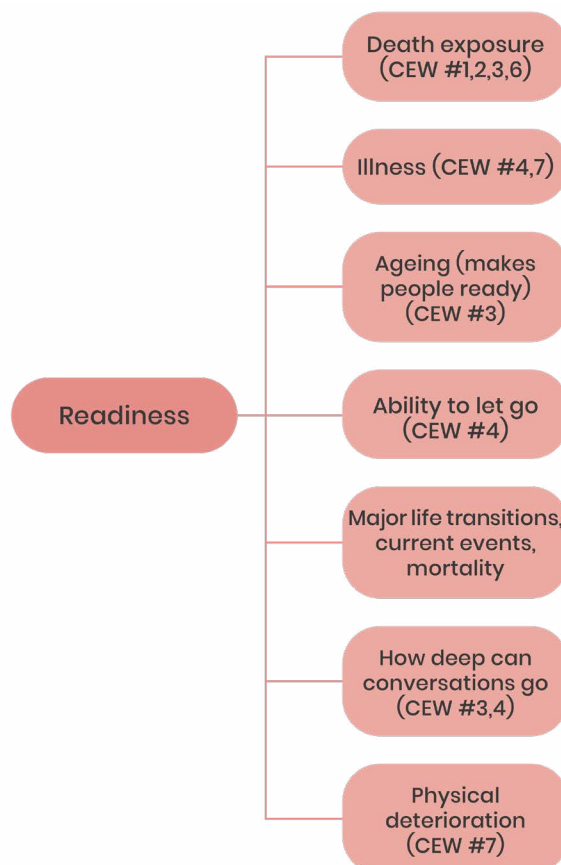
7 Distribution of Assets



As touched upon earlier, distribution of assets, particularly in relation to the issue of *faraid* which is the adherence to particular Islamic principles in the distribution of wealth proved to be a hot button topic for many of the participants. Nowhere was this starker than in the juxtaposition between the male and female participants in CEW #7, where the men largely saw religion as having conferred a natural legitimacy or privilege to them

to manage the assets, while the women fiercely contested this taken for granted assumption and were in fact more open to equitable distribution. There was also a sense among many of the participants that there was a lack of information or knowledge with regards to *faraid* principles and this greatly hindered estate planning. Timing was also brought up as a sensitive issue, further complicated by raw emotions right after a death.

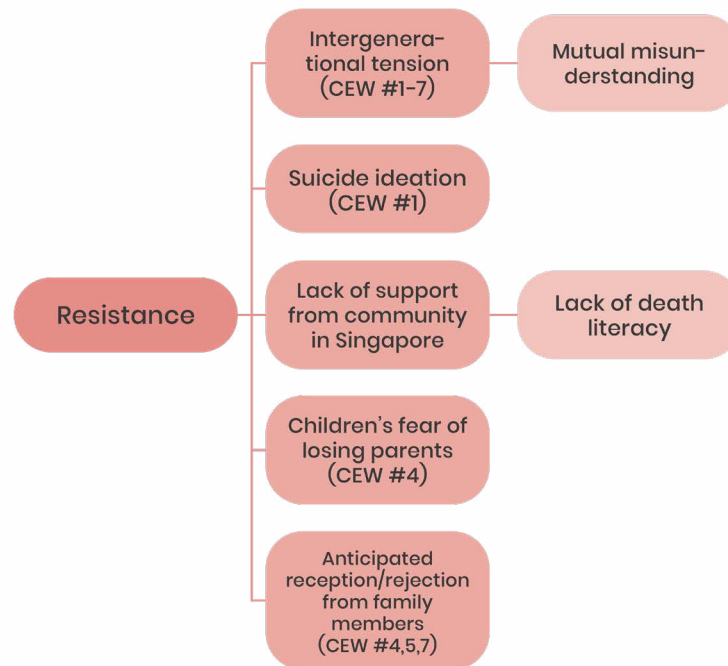
8 Readiness



Participants brought up the contrasting attitudes of readiness and resistance when posed with the question of facing death. In the case of readiness, participants described how prior exposure to death and illness predisposed them towards acceptance. Going through the ageing process and being able to let go also facilitated readiness, especially when faced with major life transitions such as marriage and childbirth, and an increasing awareness of one's own mortality, especially when accompanied by signs of physical

deterioration. However, some participants, especially those in the 31-39 age group, questioned how deep these conversations can go even for those who have signaled a readiness to engage in end-of-life discussions, especially when those around them are reluctant. This further underscores the importance of a platform such as BSN in providing the space not only for conversations, but for meaningful engagements revolving around the issue of death and dying.

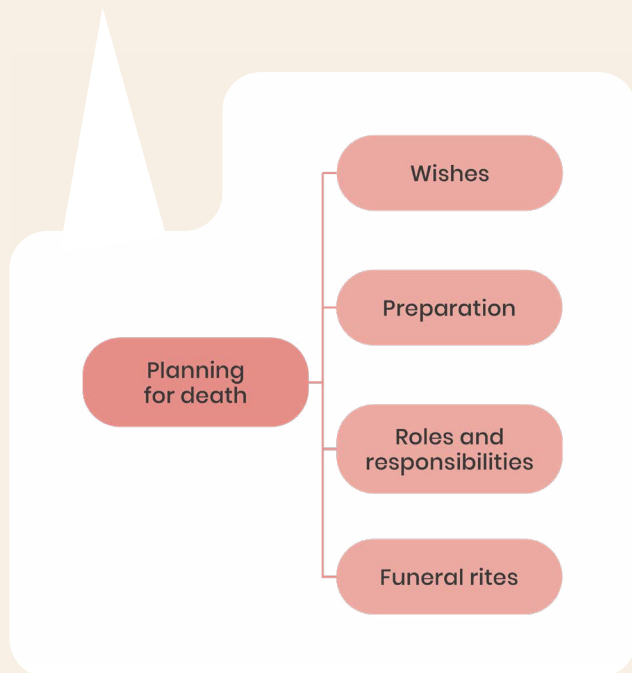
9 Resistance



Conversely, resistance was talked about by the participants in the context of intergenerational tension, relationships, and an inability to accept death. It is important to note that the issue of intergenerational tension was palpable throughout all seven CEWs, culminating in what we term as mutual misunderstanding among the different generations. This misunderstanding was particularly evident when discussing anticipated reception or rejection from family members, or when parents perceive that children are not ready to hear their

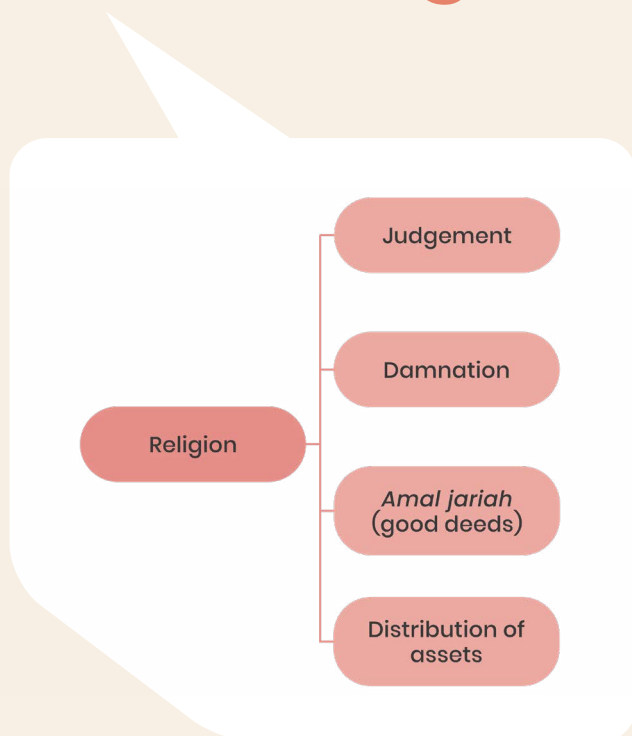
wishes, which the children verbalise as stemming from fear of losing their parents. The perceived lack of support also brings to light the lack of death literacy within the community and society in general, which the participants vocalised as not being equipped with the vocabulary and skills to be able to talk about death comfortably. Participants from CEW #1 also bring up how suicide ideation, or even discussions on the topic are quickly shut down or avoided. This will be further elaborated in Theme 14 below.

10 Planning for Death



When it comes to planning for death, participants outlined; their wishes, the preparation process, delegating roles and responsibilities to others in the management of their own death rituals and their specific preferences when it comes to their own funeral rites as important points for consideration. This is to make sure that all grounds are covered, and that their wishes and preferences are made explicit so that it can be followed, even after they pass.

11 Religion



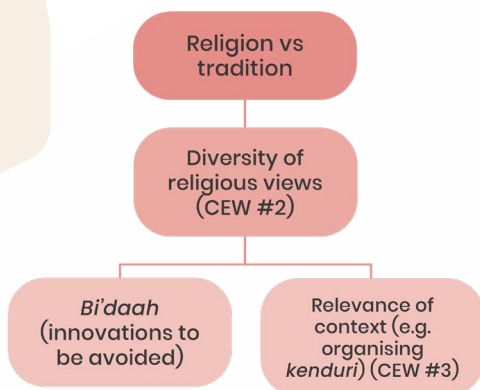
Many of the participants discussed how religion is inextricably intertwined with both their understanding of death, and the ways in which they see religion as outlining the principles which would have to be adhered to at the onset of death. This included more abstract concepts such as judgement and damnation in the afterlife, including how one is judged based on good deeds performed during their lifetime, as well as more practical matters such as distribution of assets which has been elaborated in Theme 7.



ALL GOOD THINGS COME TO A END ..
BUT THAT DOES NOT MEAN Y
- 2 MILLION people.

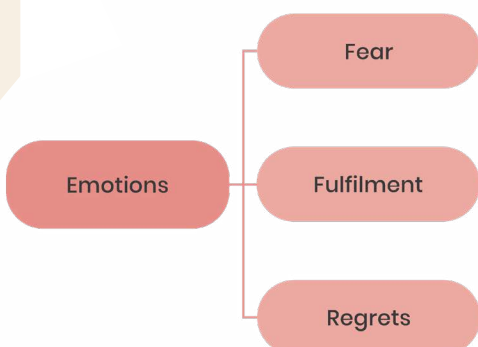
Public responding to a participatory activity at *Lepaskan Sesalan* (Release Your Regrets) public engagement event 2022 at Heartbeat@Bedok

12 Religion vs Tradition



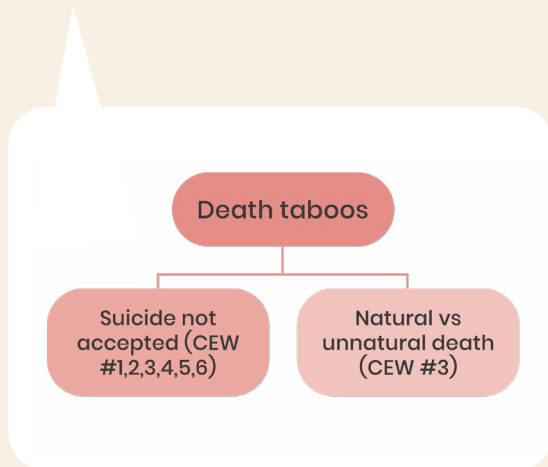
At the same time however, a number of participants also touched upon instances in which religion is seen to conflict with tradition, thus posing a dilemma when it comes to thinking about death and dying. This conflict was most evident in CEW #2 when participants engaged in a debate on the diversity of religious views, which culminated in a discussion on what was seen as *bi'daah* or innovations to be avoided, evident amidst rising conservatism in some circles. Participants in the other sessions, but most particularly in CEW #3 also touched upon the relevance of context in understanding this conflict, most importantly in sites where these contestations are most evident such as in discussing whether or not, or even in what form the *kenduri* should or should not occur. These competing demands play a major role in terms of how participants see the place of religion and tradition in the end-of-life process, while simultaneously couching it in their own understandings of its relationship to their own death preferences.

13 Emotions



Participants mentioned the manifestation of emotions primarily within the domains of fear, fulfilment, and regrets. Within the sphere of fear, participants mentioned uncertainty revolving around death and the afterlife in giving rise to these feelings, particularly when tied to the issues revolving around judgement and damnation in Theme 11. Fulfilment was expressed through a desire to bestow a positive impact on the people left behind after their deaths and gratitude on a life well lived, while regrets were contextualised in the participants' own experience of not having maximised the time with or excavated the experience of loved ones who had since passed.

14 Death Taboos



Death taboos were brought up by participants who wanted to bring issues such as suicides and what is seen as unnatural death to the fore. It was significant that suicide was mentioned in six out of seven sessions, particularly among the younger generations. The differentiated responses to what are considered natural (such as old age and illness) versus what is considered as unnatural death which is shameful or deeply hurtful and should not be openly discussed (such as suicide and when a child dies before their parents) were also debated by the participants in CEW #3. It was interesting to note that the death of children before their parents was considered as unnatural and a taboo topic to be discussed, as this does have significant impact on the grieving process as discussed in Theme 5.

15 Cultural Concepts

Cultural concepts

Fate

Amalan (deeds)

Taubat (repent)

Aib (shame)

Husnul khotimah
(beautiful closure)

Amanah (what has
been entrusted)

Fardhu kifayah
(collective duty)

Qada' and *Qadar* (what
has been ordained)

Seksa kubur
(torment in grave)

Syukur (gratitude)

The participants also listed out or raised 10 cultural concepts relevant to the Malay community, which we singled out as being especially pertinent to the discussion surrounding death and dying in the community. It is significant to note that many of these concepts do revolve around religion, which underscores the framework that religion provides in allowing the participants to rationalise, process and understand the death and dying process.



Participants engaging in a participatory activity at a Volunteer Training Workshop session

2

Thematic Overview

This section delves into the overarching themes or framework that were developed based on our analysis of the core data of the project. The core set of data comprised of information from the CEW discussions, the resource person interviews as well as the preliminary analysis that were conducted by Just Cause based on the resource person interviews.

In analysing the multiple themes and subthemes that came up from the CEW sessions as well as the resource person interviews, we noted that the multiplicity of data can be better understood if these are organised in terms of three overarching frameworks. These frameworks are also helpful in guiding the strategies and approaches that need to be developed with regards to BSN's initiatives in relation to the Malay-Muslim community. Specifically, these organising frameworks are as follows:

- A. FACTORS AT THE INDIVIDUAL LEVELS THAT SHAPE AND INFLUENCE THE PERCEPTIONS AND ACTIONS PERTAINING TO END-OF-LIFE AND RELATED MATTERS**
- B. FACTORS AT THE STRUCTURAL OR SYSTEMIC LEVELS - THAT IS FACTORS AT THE MALAY-MUSLIM SOCIAL, CULTURAL, COMMUNITY AND ORGANISATION LEVELS, ALL OF WHICH ALSO IMPACT ON THOUGHTS AND PERCEPTIONS AT THE INDIVIDUAL LEVEL**
- C. THE CONTENTIOUS FACTORS PERTAINING TO END-OF-LIFE - BOTH AT THE INDIVIDUAL AND STRUCTURAL LEVELS - FOR THE MALAY-MUSLIM COMMUNITY**

As we go through the elaborations of these overarching frameworks below to delve into the different domains and components under these overarching frameworks, it is important to ensure that we do not end up simplifying our understanding of the community's perceptions and thoughts on end-of-life. Each of the domains and components should not be understood in solo as in reality they influence and impact on one another.

Individual Level Factors

At the individual level, the factors that impacted on the individual's perceptions and actions pertaining to end-of-life issues can be organised in terms of five key domains. These include:

1. **FACTORS THAT INFLUENCE DEGREE OF MOTIVATION OR RESISTANCE TO DEALING WITH END-OF-LIFE ISSUES**
2. **INDIVIDUALS' BELIEF SYSTEMS**
3. **INDIVIDUALS' OWN AWARENESS AND KNOWLEDGE ABOUT END-OF-LIFE AND RELATED MATTERS**
4. **INDIVIDUALS' OWN SKILLS AND COMPETENCIES IN DEALING WITH END-OF-LIFE AND RELATED MATTERS**
5. **THE OPPORTUNITIES THAT WERE AVAILABLE TO THE INDIVIDUALS WHICH PREDISPOSED THE PERSON TO DELVE INTO END-OF-LIFE ISSUES**

1. **FACTORS THAT INFLUENCE DEGREE OF MOTIVATION/RESISTANCE TO DEALING WITH END-OF-LIFE ISSUES**

There were several factors that impacted on either the motivation or resistance with which an individual thought or felt about dealing with end-of-life issues. These included factors such as age, socio-economic and health status, the gender and family dynamics that the individual is embroiled in, the nature of social relationship and support that s/he has as well as the person's experiences and life circumstances.

1.1 **Age**

With regards to age, a person might feel that "it is not time yet" for him/her to dwell on end-of-life issues. The actual chronological age of the person did not necessarily have a bearing on this in the sense that a younger or older person might both have the same "it is not time yet" perspective in relation to end-of-life. In other words, a younger person might be more attuned to these issues, depending on other influencing factors which colours their own inclinations towards end-of-life and related matters.

1.2 **Health status**

Both the CEW participants and resource persons pointed out that persons whose health status were compromised and who had dealings with death or impending death were more likely to be open to talking and discussing about end-of-life matters. The situation was similar to those who had been affected by life-threatening illnesses such as cancer.

1.3 **Socio-economic status**

Findings also pointed out that a person's education and income status affected their

levels of motivation/resistance to end-of-life matters. Those with higher education and in higher income brackets were likely to be aware of end-of-life and related subjects probably due to their greater exposure to the media and other public discourses.

1.4 Social relationships and support including family dynamics

The extent, both in terms of the reach and depth of individuals' social connections also impacted their inclinations to broach end-of-life issues. Those with wider and deeper social ties as well as those whose family dynamics were supportive tended to be inclined to delve into such issues. This is understandable given the complexity of end-of-life as a subject matter i.e. one is more likely to bring up conversations about death and dying when s/he feels that those around her/him are likely to be nurturing and supportive and vice versa.

1.5 Gender dynamics

As evident from the CEW thematic analysis above, gender is a central theme with regards to end-of-life issues in the Malay-Muslim community. The dominance of men in all aspects of the community's death rites and rituals as well as estate planning matters both in terms of rights, decision making, participation and the degree to which these were imposed have an impact on a person's motivation or resistance. This was particularly the case with the women especially if they had been the main person responsible for the departed's well-being.

1.6 Previous experiences with end-of-life and related matters

Individuals' previous experiences with death and dying, whether in their personal capacities as with the CEW participants or in their professional capacities in the case of the resource persons – all influenced their predisposition to both talking about

and acting on end-of-life and related matters. Those who never had any past dealings with death and dying were less inclined to deal with these matters.

1.7 Priorities/stressors in life

The nature in which one copes with the demands of their day-to-day life such as their job, financial situations and family relations was also likely to affect both their willingness and receptiveness to consider end-of-life and related issues. They were likely to be more resistant to venture into such issues if they were already feeling the stresses of daily demands. A number of the resource persons highlighted this as one of the main reasons for the community's reluctance to delve into end-of-life issues as a whole.

1.8 Degree of complexity of each end-of-life decision making situation

Analysis of the data also indicated that the complexities of a particular situation/circumstance could also affect the willingness of persons involved to discuss or plan end-of-life related matters in advance. If the situations were complex, e.g. there had been messy divorces, difficult legal proceedings and financial disputes – those involved were less inclined to broach end-of-life planning or decision making.

2. INDIVIDUALS' BELIEF SYSTEMS

The thematic analysis of CEWs has highlighted and detailed the centrality of a belief system as a key theme in the Malay-Muslim community's end-of-life decision making. Data from the resource person interviews corroborated with the CEW findings. Individuals' cultural and religious beliefs, including their beliefs in superstitions as well as taboos around dying, death and the afterlife all shaped their attitudes about end-of-life.

3. INDIVIDUALS' OWN AWARENESS AND KNOWLEDGE ABOUT END-OF-LIFE AND RELATED MATTERS

At the individual level, the degree to which a person was aware and knowledgeable about end-of-life and related matters impacted on their willingness to deal with such matters. The more insight one has on e.g. the what, why and how of end-of-life planning and preparations – the greater the readiness to making the necessary preparations. The converse was also true, hence many of the CEW participants and resource persons raised the misconceptions that they had encountered vis-à-vis end-of-life planning. Among these included the notion that advance care planning was akin to playing God.

4. INDIVIDUALS' OWN SKILLS AND COMPETENCIES IN DEALING WITH END-OF-LIFE AND RELATED MATTERS

Our analysis also indicated that a person's skills and competencies on end-of-life issues have a substantial impact on their readiness in dealing with such matters. These skills and competencies encompassed various dimensions, all of which impacts a person's motivation or resistance to dealing with end-of-life issues. These included:

4.1 Communication skills

The level at which a person was adept at finding appropriate communication strategies to raise the complexities and sensitivities of end-of-life subjects matters. Strategies raised by participants included the use of stories and "what if" scenarios adapted from both their own sources and the wider media. Participants also indicated the usefulness of appropriate messaging when raising end-of-life and related subjects. Encouraging messaging included the prevention of family disputes prior to demise or the importance of legacy.

4.2 Emotional readiness

This refers to the degree with which a person is able to deal with the challenging situations that could arise when dealing

with end-of-life situations. End-of-life situations could evoke an expansive range of emotions from anger and denial to acceptance; or from blame to forgiveness. The depth of their emotional reservoir would influence where one is on these psycho-emotional spectrums.

4.3 Resilience and ability to cope

These qualities were also influenced by one's skills and competencies and shaped how one dealt with end-of-life issues that they encountered.

4.4 Confidence

Essentially the more skilled and competent one was with regards to dealing with end-of-life matters, the more their confidence in dealing with the practical and emotional ramifications that came up when faced with end-of-life situations.

4.5 Ability to deal with death planning and preparations

As elaborated in *15 Thematic Linkages from Community Engagement Workshops*, one of the key reasons for the challenges faced in dealing with end-of-life issues for members of the community arose due to the requirement of a speedy burial. As such, one's skills and competencies were key factors in moderating these challenges.

5. OPPORTUNITIES WHICH PREDISPOSE END-OF-LIFE CONSIDERATIONS

Our analysis indicated that the availability of certain opportunities would positively influence the likelihood of end-of-life deliberations while the lack of them would be a hindrance. These opportunities included the availability of time for introspection or self-reflection as well as the availability of safe social spaces for end-of-life considerations. As such, a person whose day-to-day life's demands were overwhelming or whose social networks were averse to end-of-life discussions was less likely to dwell on end-of-life matters versus those who had the time and space to do so.



Research participants at a Community Engagement Workshop session

Structural/Systemic Level Factors

The multifaceted structural or systemic level factors that affected the Malay-Muslim community's perceptions and actions around end-of-life as evinced from the data can be categorised under six main domains including:

1. **CULTURAL CONCEPTS PERTAINING TO END-OF-LIFE**
2. **SOCIAL EXPECTATIONS IN RELATION TO DEATH AND DYING**
3. **RELIGIOUS INJUNCTIONS AND GUIDANCE**
4. **ENDORSEMENTS BY THE LEADERSHIP OF THE MALAY-MUSLIM COMMUNITY**
5. **RESOURCE CONSTRAINTS AMONG THE MALAY-MUSLIM COMMUNITY**
6. **LIMITATIONS IN THE MALAY-MUSLIM COMMUNITY END-OF-LIFE LANDSCAPE**

1. CULTURAL CONCEPTS PERTAINING TO END-OF-LIFE

As highlighted in the thematic analysis of the CEWs, death for the Malay-Muslim community is not an end but a beginning. Furthermore, it is a beginning that has no end, that is, a beginning to a life that is eternal. As such one's death, more than anything else is a passage between a temporary physical life on earth and a permanent one in *akhirah* (after life on earth). The journey of a Malay-Muslim's life is in fact a preparation for the eternal life and this journey is richly guided by cultural/religious concepts which are intertwined in their relevance towards life and death. As highlighted through the findings in the CEW and resource person interviews, many of these concepts are widely held among members of the community and are major preoccupations not only with end-of-life considerations but also in life more generally. These concepts were previously elaborated in Theme 15 within *15 Thematic Linkages from Community Engagement Workshops*.

2. SOCIAL EXPECTATIONS IN RELATION TO DEATH AND DYING

Due to the dominance of cultural and religious concepts as well as their specificities which governs all aspects of death and dying in the Malay-Muslim community, many felt the weight of social expectations when dealing with such situations. This is evident across the CEW participants and resource persons.

The injunction on the need for burial ideally within 24 hours alone made the logistics around death very stressful for those who had to handle the funeral; especially for persons who were already not in their best emotional state given their grief. Permit for a burial site needed to be sought; the final rites conducted, transport arranged, and *tahlil* (group prayer recitation

sessions usually accompanied by a meal) had to be held all within the day of the death. Beyond the expectations for these logistics to be fulfilled in a manner that the community considered appropriate and dignified, other social obligations included having to ensure that everyone relevant, including extended families and friends, were informed about the death.

As highlighted in previous segments, given that death in the Malay-Muslim community is not a personal but a social matter with the involvement of an extensive network of kin and friends, the funeral rite itself is a process riddled with social expectations keenly felt by those directly involved in seeing through the various rites. This gave rise to some of the sentiments expressed particularly among the younger CEW participants that there is no room for agency or choice in the death and dying process for the Malay-Muslim as every aspect of it was predetermined by the larger community.

3. RELIGIOUS INJUNCTIONS AND GUIDANCE

Many of the CEW participants and resource persons also asserted that beyond the cultural and religious concepts as well as social expectations that delineated the community's ideas and practices of end-of-life, these ideas and practices are also affected by Majlis Ugama Islam's (MUIS) issuances. These could be in form of *fatwas* (rulings), or *irsyads* (opinions). Specific to end-of-life matters there are *fatwas* issued by MUIS on distribution of assets post-death as well as on organ donation. These *fatwas* are a strong source of reference for the community as a whole.

Beyond *fatwas*, MUIS has also issued *irsyads* or advisories to guide the community on decision making regarding particular issues. *Irsyads* instead of *fatwas* were issued when there was no conclusive agreement among sources of reference on a particular issue. With respect to end-of-life and related matters – MUIS issued an *irsyad* on advance care planning indicating that members of the community could have the freedom to undertake an advance care plan if they deemed this to be fit.

4. ENDORSEMENTS BY THE COMMUNITY'S LEADERSHIP

Other than MUIS, participants and resource persons raised the significant role played by other Malay-Muslim bodies as well as groupings of individuals pertaining to the community's end-of-life considerations. One of these bodies highlighted is the recently constituted M3 – a collaboration between MUIS, MENDAKI (Council for the Development of Singapore Malay/Muslim Community) and MESRA (People's Association Malay Activity Executive Committee Co-ordinating Council). Other leadership groupings of relevance to the community on pertinent matters include the Malay-Muslim members of parliament and the *asatizahs* (Islamic religious teachers). An interesting development to note is the point raised by some that the more formally educated members of the community would not just look towards one particular body or grouping including MUIS for reference but would balance views from the different sources.

5. RESOURCE CONSTRAINTS AMONG THE MALAY-MUSLIM COMMUNITY

Quite apart from the concepts, social expectations, injunctions, advisories and teachings on end-of-life issues raised above, a number of the participants particularly those from the resource person group pointed out that on the whole, the issue of end-of-life is not high on the community's agenda. They opined that the community is confronted by an array of more immediate and pressing issues such as lack of educational attainment, inadequate financial resources as well as other social issues. They thought that these more urgent challenges severely limit the resources that are available for matters such as end-of-life. This lack of focus consequently accounted for the lack of information and hence awareness among Malay-Muslims about the relevance of end-of-life deliberations.

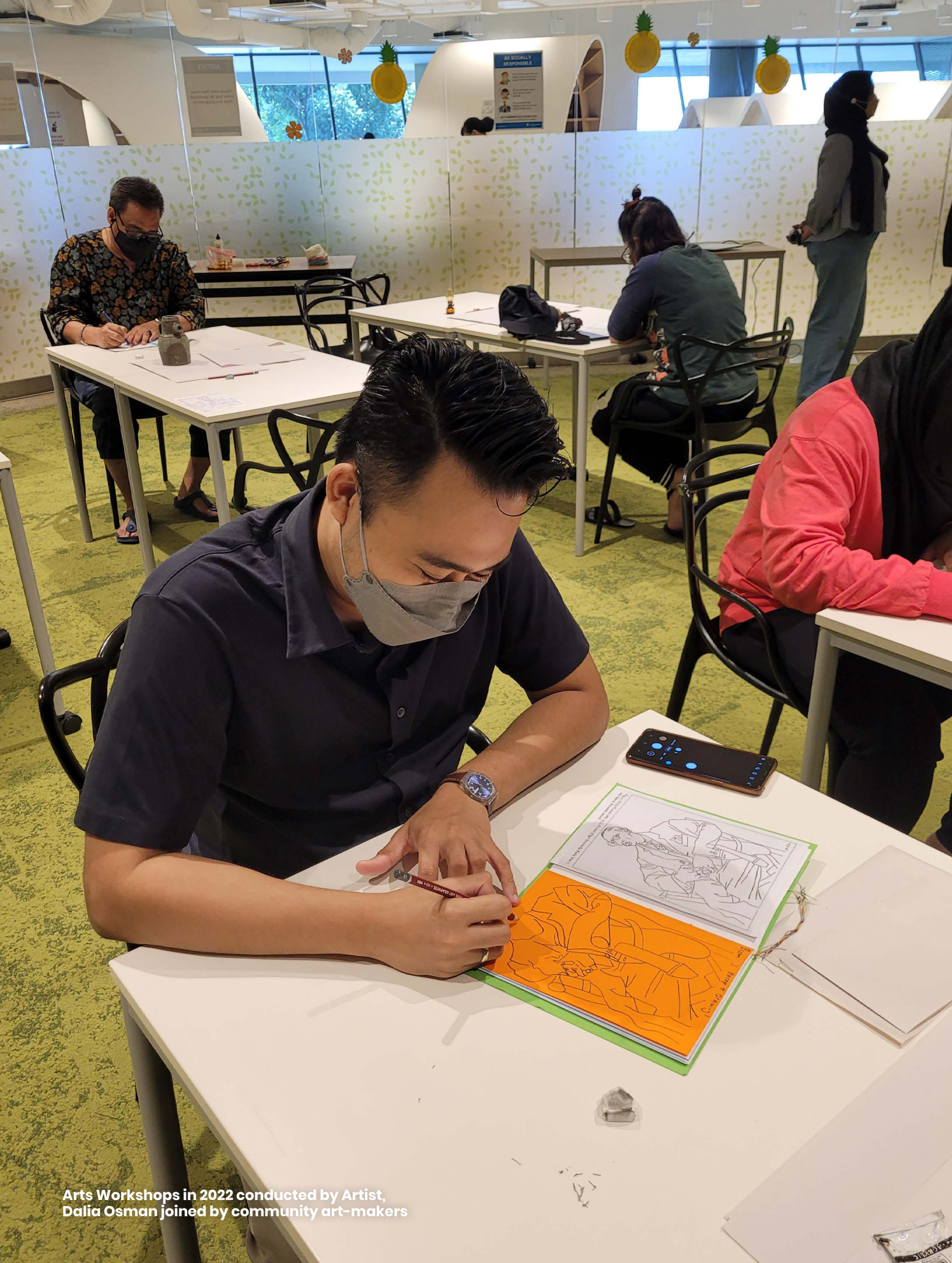
6. LIMITATIONS IN THE MALAY-MUSLIM COMMUNITY END-OF-LIFE LANDSCAPE

A related issue raised by a majority of the participants was the severe lack of community specific end-of-life resources. The limitations cut across every spectrum of end-of-life and related needs including Malay-Muslim lawyers, care professionals, advance care planning facilitators as well as facilities such as hospices. This was considered a significant issue as the community was generally reluctant to tap on the mainstream

end-of-life resources given the indelible ways in which death and dying are intertwined with the community's cultural and religious beliefs and practices. There was a very valid assumption that only those who know and understand the community's cultural and religious beliefs and practices would be able to provide appropriate guidance on this complex and sensitive subject. The lack of coordination between the few available services often resulted in further challenges with access and enrolment for those in need.



Artist Hasyimah Harith from P7:ISMA engaging with elders from Montfort Care – GoodLife! Bedok during an Arts Workshop session



Arts Workshops in 2022 conducted by Artist, Dalia Osman joined by community art-makers

Contentious Factors Impacting on Malay-Muslim Community End-Of-Life Considerations

Our analysis highlighted that there are numerous factors both at the individual as well as familial, community and societal levels which made end-of-life and related considerations complex and problematic for the community. In this section, we aim to unpack some of these factors to provide insights into the possible reasons for the contentions which arose in relation to such matters in the Malay-Muslim community.

1. **SELF-PERCEPTION VERSUS PERCEPTIONS OF OTHERS**
2. **MATCHING OF END-OF-LIFE AND RELATED WISHES AND PREFERENCES**
3. **THE END-OF-LIFE DECISION MAKING PROCESS**
4. **GRIEVING PROCESS**
5. **FAMILY'S WILLINGNESS AND READINESS TO ENGAGE**
6. **BURDENING THE FAMILY**

1. SELF-PERCEPTION VERSUS PERCEPTIONS OF OTHERS

As highlighted in earlier segments, death and dying in the Malay-Muslim community is not an individual nor just a familial matter but that of the wider community. The rites and rituals involved with death and dying were prescribed in detail with hardly any room for personalisation. As expressed almost unanimously by the CEW participants and resource persons, an individual was almost always highly conscious of the views of not only the extended kin networks but the thoughts and perceptions of the wider community on particular aspects of end-of-life decision making. The fear of being judged by these wider networks more often than not weighed heavily on the individual. The individual's gender and place within this kinship network e.g. young versus elder all affect the end-of-life decision making process of the individual member.

2. MATCHING OF END-OF-LIFE AND RELATED WISHES AND PREFERENCES

Over and above the real and immediate ways in which the perceptions of the wider networks impact the individual's end-of-life decision making process, participants also cited other end-of-life related dynamics that would often complicate the situation even further. These included:

- The need to consider the preferences and wishes of the living versus the ones who are dying which in many cases were not similar
- The need to consider medical prescriptions versus the wishes of both the individuals and the wider networks
- The need to consider the cultural norms and/or religious obligations versus the wishes of the individuals and the wider networks

3. THE END-OF-LIFE DECISION MAKING PROCESS

Analysis of the data also highlighted that the decision making process itself was often fraught with contentions as it was impacted by a myriad of factors which could pit members against one another. These factors ranged from the personal to the structural including the following:

- Gender – as highlighted in *15 Thematic Linkages from Community Engagement Workshops*, males hence sons, husbands and uncles often dominated the decision making process while they might not have been involved in the care process and hence unaware of the wishes and preferences of the dying
- Order of birth – eldest or first born perceived as having primacy in decision making
- Education – the educated were perceived as more knowledgeable about decisions that needed to be made
- Income – those with the availability of means to contribute to the care process were seen as more caring
- Importance of shared decision making – leading to differences and conflicts about what needs to be done
- Pre-existing family conflicts – would render further complexity to end-of-life discussions among members
- Involvement of professionals (healthcare

personnel, Advance Care Planning facilitators, social workers) – could aid but also abet an already contentious situation

- Cultural/religious beliefs and practices – the belief in divine interventions through prayers versus medical interventions

4. GRIEVING PROCESS

End-of-life situations are inherently challenging at all levels – physical, financial but most particularly at the psycho-emotional levels. Everyone involved are inevitably aggrieved yet almost all the participants from both the CEW and resource person groups raised the lack of available space and opportunity to grieve. The ambivalence towards grief expressions was a factor that participants found problematic as the inability to process deep-seated feelings affected them psycho-emotionally in unexpected ways and over a long period of time. Typically, participants felt that the grieving process is truncated by various factors which included:

4.1 Brevity of the funeral service

The religious requirement for a quick burial meant that those involved were preoccupied with the logistics of dealing with the departed which allowed for little to no space for grieving. This lack of opportunity was augmented by the slew of belief and practises which discouraged public expressions of grief.

4.2 Responsibility of being “the strong person”

Another factor which participants felt impeded their ability to grieve was the expectation for them to be “the strong person”. This expectation could be a legacy of the departed as much as those left behind. As one of the CEW participants highlighted, she along with her siblings were expected by their departed father to be “the strong ones” for their mother.

4.3 Personal versus professional boundaries

Another impediment to grieving that resource persons raised was the expectation that as professionals working in relation to end-of-life, they were expected to have the capacity to keep their grief in check as opposed to others. These participants expressed the difficulties they faced dealing with their grief due to the expectations of those around them.

4.4 Death acceptance and its implications

As pointed out earlier, there is an ease with which many Malay-Muslims accept death given that it is a passage to an eternal life. This ease of death acceptance however has inadvertently led to an undermining of end-of-life and related considerations among the community. Hence, as expressed by almost all the participants – there is little discussion or emphasis paid to matters such as end-of-life planning, treatment preferences and different options. As such, we found many among the participants, including professionals working in the field themselves have neither made their own end-of-life plans nor discussed end-of-life matters with their loved ones.

4.5 Relationship and trust

Another factor which could give rise to conflict and tension in relation to end-of-life matters was the degree of trust as well as social connection and support that was available at the familial (both immediate and extended) as well as the community levels. Where there is a lack of trust and connectedness among family members, end-of-life discussions tended to be rife with discords and disagreements. The weak ties made it difficult for members to resolve issues that are inherently complex. Similarly, when trust and ties were fragile at the community level, there would be dissensions with regards to beliefs and ideas on end-of-life with every subgroup holding to its own.

5. FAMILY'S WILLINGNESS AND READINESS TO ENGAGE

Another related dimension at the familial level which participants pointed as sources of contention was the family's willingness and readiness to engage in such matters. Participants thought that several factors had bearing on this degree of willingness and readiness. These included:

- The availability of information, resources and support – in that families that had access to the needed information and support were more likely to be open to end-of-life deliberations given their level of awareness and confidence
- The availability of time and space – among members of the family would positively influence the degree of willingness
- The generalised assumptions held by family members – that their kin would know what to do in the event of a demise on the other hand served as an impediment to the willingness

6. BURDENING THE FAMILY

The fear of burdening the family was another factor that complicated end-of-life decision making. Both CEW participants and resource persons spoke about the overwhelming reluctance by many to impose on their family. Many participants also expressed their own reluctance to burden their kin. Some of the reasons cited was the potential costs of treatment such as life support as well as the costs (both financial and time) of caregiving. The reluctance was due to the need to prioritise the needs of the family. The flip side of this fear and reluctance on the part of the departing was the willingness of family members including extended kin to do as much as they could hence leading to tensions at the end-of-life.



Sukar (Melepaskan) - Mendakap Kenangan
Forum Theatre at *Lepaskan Sesalan (Release Your Regrets)* public engagement event 2022 at Heartbeat@Bedok

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6 Archetypes

Definition and Purpose of Archetypes to Programme Development

The concept of ‘archetype’ has been widely used in anthropological studies to tease out the influence of culture in human development as well as systems of meaning and interpretation that are grounded in human experience across cultures. Archetypes are developed based on observable patterns of human behaviours. Each archetype exists as a form of a mental construct; classifying and comparing individuals/cases with similar attributes, dispositions and experiences. The use of archetypes provides deeper and nuanced insights into the experiences of diverse groups of individuals including their needs and concerns and the ways in which they embody, approximate, contest or negotiate social reality. In consumer research or advertising, archetypes aim to promote authenticity by conveying shared values that consumers can relate to and believe in, and cultivating connection through a recognisable and relatable archetype.

In this project and specific to programme development, we use archetypes to (i) identify and unpack issues and needs specific to end-of-life experiences in the Malay-Muslim community and (ii) develop culturally competent end-of-life resources that appeal to the needs and concerns of diverse individuals in the Malay-Muslim community. Developing content that reflects the experiences detailed for each of the archetypes will allow the reader or audience to connect certain parts of themselves with the character. This process promotes awareness and engagement in approaching end-of-life issues, and also to observe parts of their own selves, mirrored through the archetypes, that they may not have considered before.

Readiness to Engage with End-of-Life Issues: Different Starting Points

DIFFERENT STARTING POINTS OF READINESS	DESCRIPTION
“Wants to talk but don’t know how/find it difficult to”	Individuals who are curious about/have some exposure to end-of-life issues/interested, see the importance of, or motivated to discuss the issues but lack opportunities, strategies or skills to do so
“Just don’t like to talk about it”	Individuals who find talking about end-of-life as ‘taboo’ or inappropriate subject matter
“It’s too painful/emotional to talk about it”	Individuals who have had exposure to death/aversion to loss/negative interactions and express difficulty when engaging in such topics
“No capacity to talk about it”	Individuals who are overwhelmed or preoccupied with day-to-day survival e.g. money, job, caregiving and do not have the bandwidth to think about, much less bring up end-of-life issues in conversations
“Never thought about it”	Individuals who are not aware of end-of-life issues and/or do not see end-of-life as an issue that concerns them

Table 3.
Starting Points of Readiness to Engage with End-of-Life Issues

Based on their preliminary analysis of resource persons interviews, Just Cause had initially constructed five key profiles around one’s readiness to engage with end-of-life issues in the Malay-Muslim community. After triangulating the preliminary analysis from resource persons interviews with participant observation during the CEW sessions, we generated Table 3 which highlights the different starting points of readiness, with detailed descriptions.

Based on our observations during the CEW sessions, our analysis concurs with findings from Just Cause but we find it more accurate

to suggest that what Just Cause had earlier constructed as different “archetypes” may be better specified as different stages or starting points of readiness to engage with end-of-life issues. The reason being, the context and circumstance for different starting points will differ based on the needs and experiences of diverse members of the Malay-Muslim community. Hence, it will be more productive to nest differentiated starting points within an archetypal construct rather than conceptualise starting points as an archetype in, and of itself.

6 Archetypes Encompassing Diverse End-of-Life Experiences and Needs in the Malay-Muslim Community



Caregivers



Avoidant family members



Dominant men



Disempowered family members



Close-knit families



Individuals who work in areas that encompasses death/dying

Dominant archetypes signalling diverse experiences and needs for engaging in end-of-life issues

We constructed the dominant cultural archetypes based on the diverse differentiated needs and experiences that came up during the CEW sessions as well as from the resource persons interviews. Our analysis indicates different starting points of readiness across each of the six dominant archetypes. By outlining the dominant archetypes and acknowledging different starting

points within each archetype, programme content for BSN can be pitched better in terms of relevance and resonance to members of the Malay-Muslim community. To facilitate this process, our team has identified key needs or challenges within each archetype that will be further elaborated in the next section.

1. CAREGIVERS

Caregivers refer to individuals who are recognised by family members as those who are providing care to their loved ones, who may or may not be at the end-of-life. Not all caregivers are decision makers – some may not have the autonomy or legitimacy to make care decisions on behalf of their loved ones. Other variables such as gender, birth order, family dynamics and hierarchy as well as religious knowledge influence caregivers' decision making roles. The following key factors determine caregivers' engagement with end-of-life issues:

1.1 Awareness

Caregivers may lack awareness of available resources to support their loved ones at the end-of-life.

1.2 Access to informed choice

Caregivers not feeling confident that they have enough information at hand to make decisions pertaining to end-of-life leading to instances of decisional regret where they find themselves doubting if they are making the 'right choice' or if they are even in a legitimate position to make the choice.

1.3 Role as decision maker and balancing needs or wishes of loved ones vis-à-vis their own

Caregivers are often regarded as the proxy in terms of decision making for their loved ones. They find themselves saddled with questions pertaining to the needs and wishes of their loved ones, especially in terms of dealing with conflicting wishes (of their own versus that of loved ones) and asking if they are imposing or projecting their needs/wishes onto their loved ones.

1.4 Bandwidth/capacity

Caregivers are so bogged down by the day-to-day responsibilities and emotional load of caregiving that they do not have the bandwidth or capacity to engage in end-of-life conversations especially if it is not directly related to the current circumstances of their loved ones.

1.5 Existing family stressors

Caregivers have to navigate multiple expectations from other family members including whether they have the autonomy and legitimacy to make decisions. The fear of being blamed for undertaking certain decisions was also a strong undercurrent; doubting if they are making the 'right choice' or if they are even in a legitimate position to make the choice.

1.6 Sensitivity around talking about end-of-life and death taboo

Caregivers who bring up end-of-life in conversations about their loved ones may be seen as wanting to be free from their caregiving responsibilities e.g. wishing for death on their loved one to ease the caregiving burden. Talking about end-of-life may be associated with making a *doa* (prayer) for the loved one to die.

1.7 Cultural dilemmas about caregiving duties

Caregivers experience guilt when they show interest in end-of-life issues and feel like they are not permitted to imagine or anticipate their loved one dying. Caregivers also receive backlash or accusations of being unfilial and/or not making the effort (*usaha*) to continue caring for their loved ones, including conserving resources e.g. money for their benefit rather than ensuring continued treatment for the loved one.

1.8 Anticipatory grief

Caregivers who are already mourning the loss of their loved ones even before they die, due to physical and/or cognitive deterioration and/or impairment, may be more prepared to discuss end-of-life as they view death as impending.

2. AVOIDANT FAMILY MEMBERS

This refers more specifically to spouses and children who avoid conversations related to end-of-life and/or are not prepared to talk about end-of-life issues.

2.1 Spouse

Existing household relationship dynamics and gendered division of labour influence differences in degrees of death acceptance between spouses, including the emotional weight of being the one left behind and having to cope with responsibilities such as managing household finances and caring for children. Older women spoke about being dismissed by their husbands when conversations steer towards end-of-life topics. Husbands are perceived to be more dependent on wives for emotional and domestic support and therefore, less prepared to confront losing their spouses.

On the other hand, children described how spousal loss, for mothers/wives, had more to do with having a companion or financial support. For both men and women, end-of-life conversations may also trigger concerns or anxieties about having had adequate preparation for the afterlife, which spouses may not be ready to deal with, especially when they

have other immediate concerns in the current life.

2.2 Children

We noted some intergenerational tension between parents and children across all CEWs, mostly around the assumption that end-of-life is a sensitive topic. Yet, we also found that children, as with parents, would like to discuss end-of-life needs but were unsure about the appropriate approach to broach the topic. Children cited difficulties engaging in end-of-life conversations and expressed discomfort due to sensitivities, potential conflict with regards to inheritance/distribution of assets (*faraid*) or accusations of eyeing their parents' wealth.

The lack of death acceptance was more prevalent among children compared to parents. Children may not want to imagine losing their parents or their parents' death as they are not ready to assume the responsibilities of caring for the living parent or taking over the companion role. The stress of having to know and remember death rituals or funeral rites was also mentioned in the CEWs.

2.3 Parents

Parents who avoid end-of-life conversations with children expressed confidence and trust in the latter to carry out their wishes at the end-of-life. Some older women (CEW #7) argued that assumptions may lead to potential conflict, and it is best to make wishes explicit. Yet, the women who raised the point have not had the conversation with their family members. Some of the issues include:

- Not wanting to burden or make their children feel sad
- Unable to find suitable opportunities to raise end-of-life topics/discussions; not the right time or not wanting to "kill the mood"
- Lack of confidence or ability to process own and others' emotions before, during and after end-of-life conversations

3. CLOSE-KNIT FAMILIES

The social workers interviewed for this study shared their experiences initiating conversations on end-of-life needs so clients who were estranged from their families were able to get their wishes fulfilled. Conversely, in close-knit families, there was the opposite effect of multiple voices wanting to be involved at end-of-life. Among these families, there is a hierarchy in terms of who gets to make or gatekeep decisions, based on gender, birth order, caregiver status, qualifications or knowledge, and socio-economic status. Having multiple people involved comes with managing different expectations and taking care (*jaga hati*) not to exclude or offend any family member.

Additionally, the paradox of close kinship ties means that family members are complacent in assuming that each knows what the other wants, contributing to the perception that end-of-life conversations are unnecessary or indicates lack of trust.

Close-knit families may also find it difficult to engage in end-of-life conversations due to the fear of loss of kinship or change in kinship dynamics especially if loved ones are the anchor. In CEW #4, for example, a woman shared how her extended family started to drift apart with the loss of her grandmother.

4. DOMINANT MEN

Dominant men refer to male family members who are perceived to be the leader or occupy authoritative status in the family. Men who identify with this archetype tend to monopolise the decision making process around end-of-life. They believe in their right to make decisions by virtue of being the elder male e.g. uncles, brothers.

This status may be self-conferred and/or legitimised by other members in the family.

In discussions about end-of-life planning, these men have a tendency to defer to *faraid* because they are secure in the knowledge that Islam sanctions their rights to inheritance and also other rituals surrounding death e.g. older men in CEW #7. Men who are perceived or perceive themselves to be dominant cannot be seen as emotional when confronted with loss or be seen as affected by the death of a loved one. They were also more inclined to describe women as weaker and more emotional. Younger men who are uncomfortable by the gendered expectation of emotional strength described how grieving for men is largely unspoken or silenced. Dominant men tend to assume the role of the provider and protector – when a loved one dies or even after they die.

5. DISEMPOWERED FAMILY MEMBERS

Disempowered family members are those who feel like they are not in the position or have a right voice to make decisions pertaining to their loved ones, hence they do not initiate end-of-life conversations. Sons in CEW #3, for example, brought up examples of older women in the Malay-Muslim community who they felt lack autonomy throughout their lives. These women have had someone making decisions for them and have been conditioned to believe that their views are not important. Familial disempowerment is also attributed to the intersection of various factors such as age, income and education status, religiosity, gender, birth hierarchy, sexuality and marital status, that contribute to members feeling like their sense of rightful belonging in the family is tenuous.



Forum theatre marketing image as part of *Lepaskan Sesalan* (Release Your Regrets) public engagement event 2022 at [Heartbeat@Bedok](https://www.heartbeat.org.my/)

6. PROFESSIONALS WHO WORK IN AREAS THAT ENCOMPASS DEATH/DYING

Some resource persons interviewed, including healthcare professionals and social workers, seem to have internalised their own prejudice or assumptions about the community. Common examples include statements that Malays, unlike the dominant Chinese group do not do advance care plans (ACP). However, the literature on ACP highlights that resistance to ACP applies to all ethnic groups and is not specific to Malays.

As Malays, and often, a token in their professions, these professionals are expected to keep a distance from the community e.g. having cultural advantage as it blurs boundaries of professional versus personal, but yet expected to know everything about, and be the representative of the community.

Despite highlighting resistance from the Malay-Muslim community about end-of-life planning, professionals themselves are not prepared to confront their own end-of-life process. They also expressed difficulties in bringing up end-of-life topics with their own family members (lest they are accused of allowing

work to encroach into personal spaces). Other difficulties include having to reconcile professional duties with personal and religious expectations e.g. a social worker feeling unprofessional that she broke down in front of a family member because she recalled her father's end-of-life journey.

There is also a need for space to process traumas/grief when encountering difficult deaths at work. Professional duties make it difficult for them to engage fully with end-of-life issues with clients or with family members, as there is a lack of bandwidth due to high caseloads. On the other hand, it is also difficult to get buy-in from clients' family members. Even with support from clients, professionals may not consider themselves qualified to aid clients and/or their family members because of the strong association between death and the religious domain. A nurse described how her aims of not wanting her patients to suffer at the end-of-life ran contrary to other family members' views.

Professionals also cited the lack of support from community leaders and also a lack of trust in the healthcare system to alleviate suffering and pain.

Conclusion



Self-drawn portraits of community art-makers presented in *of life and legacy* exhibition at *Lepaskan Sesalan (Release Your Regrets)* public engagement event 2022 at Heartbeat@Bedok

The archetypes outlined in this section provide cultural contexts to the diverse experiences and engagement with end-of-life issues in the Malay-Muslim community. We acknowledge that the six archetypes are not specific to the Malay-Muslim community but have universal appeal across the different ethnic communities in Singapore. At the same time, the practices, attitudes and behaviors around end-of-life, manifested through the different archetypes, reflect particular social

structures and cultural norms that individuals and families are embedded in. Thus, the major contribution of our findings is in making sense of the ways that Malay-Muslim members from diverse backgrounds draw upon their personal experiences with end-of-life while also contextualising their views within larger social structures and cultural practices around death, dying and kinship in Singapore.



Kembali dance performance by elders from Montfort Care - GoodLife! Bedok and dancers from P7:ISMA, at *Lepaskan Sesalan* (Release Your Regrets) public engagement event 2022 at Heartbeat@Bedok

4

Programme Recommendations

Our study proposes two different types of programme outcomes – at the (i) individual and (ii) community level that BSN can use as indicators for successful programme evaluation. We generated the outcomes based on the key gaps and concerns raised by the participants and from our own thematic analysis of the CEW observations, triangulated with data from resource person interviews.



Kata-Kata Kita
Variety Show 2021 at
Aliwal Arts Centre

AT AN INDIVIDUAL LEVEL

Outcomes include:

- Having access to end-of-life related arts-based interventions that appeal to audience's cultural sensitivities
- Having knowledge and awareness of the death and dying process
- Develop skills and competences in communicating end-of-life preferences and facilitate such conversations among loved ones
- To be able to reflect on a meaningful ending for oneself and also of loved ones
- Understand needs for emotional well-being as well as grief in approaching or dealing with death and dying

AT THE COMMUNITY LEVEL

Outcomes include:

- Having an inventory of culturally relevant end-of-life resources for the community
- Community awareness of resources that can support or facilitate end-of-life planning
- Development of a culturally competent end-of-life toolkit to sensitise volunteers and/or advance care planning facilitators to issues and challenges in the Malay-Muslim community
- Clarify or address misconceptions surrounding death/dying and end-of-life e.g. death taboos, *usaha* (effort) versus suffering, palliative care
- Demonstrations of the parallels and intersections of the end-of-life experience within the Malay-Muslim community and linking it back to the wider Singapore end-of-life experience i.e. going beyond assumptions that issues are specific only to the Malay-Muslim community or essentialising these as the "Malay problem"



Self-portrait by Arts Workshop participant, as part of *of life and legacy* exhibition, *Lepaskan Sesalan (Releasing Your Regrets)* public engagement event 2022

5

Proposed Programme Theory to Promote End-of-Life Engagement in the Malay-Muslim Community

To achieve both the individual and community level outcomes, the design and implementation of specific interventions (programme input) need to consider the interplay of both the context and mechanisms of the programme.

Working Definitions

CONTEXT

Refers to the condition, context and setting in which Malay-Muslim community members engage with end-of-life issues. In this study, the six archetypes form the context informing the design of interventions that should be tailored to the needs of individuals whose circumstances align with the archetypal constructs. Interventions that do not resonate with the archetypes/context may be less appealing to Malay-Muslims as they may be viewed as unfamiliar or irrelevant to their circumstances.

MECHANISM

In this study, the five different stages of readiness to engage in end-of-life conversations were identified as generative mechanisms. The five stages apply to each context/archetype. For example, within the caregiver archetype, there are individuals who (i) do not like talking about end-of-life; (ii) wants to talk about end-of-life but find it difficult to broach the topic; (iii) find the topic too painful or emotional to discuss; (iv) do not have the capacity to discuss end-of-life or (v) never thought about end-of-life. Since there are different mechanisms in which individuals engage with end-of-life, interventions for each of the archetypes require some scaffolding so the activation needs of individuals, who are at different levels of engagement within the archetypal construct, can be met.

INPUT

Once the context and mechanisms of the programme have been identified, programme developers can design and assess how their proposed programme content/intervention meets the needs of the specific sub-groups of the target population and refine the programme to address possible blind spots. Inputs are defined as the resources and activities i.e. intervention required to implement a programme that works for the target population.

OUTCOMES

Outcomes are derived based on identifying key gaps in the area of intervention/research and understanding what the target population needs, and what the programme can realistically achieve. Outcomes need to match the context, mechanism and intervention/inputs described. Outcomes will not be achieved without pathways that link together the contexts and mechanisms with appropriate input/interventions.

CONTEXT (ARCHETYPAL CONSTRUCT)	MECHANISM (STAGES OF READINESS)	INPUT (SPECIFIC INTERVENTIONS)
Caregivers	<ul style="list-style-type: none"> ● Wants to talk but don't know how/find it difficult to ● Just don't like to talk about it ● It's too painful/emotional to talk about it ● No capacity to talk about it ● Never thought about it 	<p>Examples:</p> <ul style="list-style-type: none"> ● Social media engagement ● Digital and physical platforms ● Funding ● Community partners ● Influencers ● Podcast ● Forum theatre ● TV series
Avoidant family members		
Close-knit families		
Dominant men		
Disempowered family members		
Professionals who work in areas encompassing death/dying		
OUTCOMES		
<p>Individual level:</p> <ul style="list-style-type: none"> ● Arts-based interventions that appeal to audience's cultural sensitivities ● Knowledge and awareness of death and dying processes ● Able to communicate end-of-life preferences and facilitate such conversations among loved ones ● Able to reflect on a meaningful ending for oneself and loved ones ● Understand needs for emotional well-being in approaching or dealing with death and dying <p>Community level:</p> <ul style="list-style-type: none"> ● Inventory of culturally relevant end-of-life resources for the community ● Awareness of resources that can support or facilitate end-of-life planning ● Culturally competent end-of-life toolkit to sensitise volunteers and/or advance care planning facilitators to issues and challenges in the Malay-Muslim community ● Clarify misconceptions surrounding death/dying and end-of-life ● Demonstrate parallels and intersections of end-of-life experience in the Malay-Muslim community and linking it back to the wider SG end-of-life experience 		

Table 4. Proposed Programme Theory



Audience member at *Lepaskan Sesalan* (Release Your Regrets) public engagement event 2022 at Heartbeat@Bedok

6

Annotated Resources and Further Reading

A. Annotated Resources

The articles in this section provide some background information and cultural context that complements the findings of the report. We included brief summaries of each article and highlight key references or findings that may be relevant to programme development. Most of the articles are written about Malay-Muslim communities in Malaysia and Indonesia, but the cultural knowledge and structural systems around death and dying are congruent to existing practices in Singapore.

DEATH AND DYING IN MALAY-MUSLIM COMMUNITIES

- **Schreiber, J. (2015). Biomedicine as Global Assemblage: The Malay Muslim Account of Total Brain Failure. *Die Welt Des Islams*, 55(3/4), 312–347. <http://www.jstor.org/stable/24893434>**

Importance of considering both global and local conversations in understanding death, as well as biomedical and religious/traditional debates around death and dying in the context of life-sustaining technologies. With regards to total brain failure, there is clear contrast between official “fatwas” that equate ‘brain death’ with death and rural Malay-Muslim communities which perceives ‘brain dead’ patients as dying people. Highlights the multiplicity of discourses among the Malay-Muslim majority in Malaysia and the tensions that emerge as a result. Draws upon cultural notions of the body and death and the ways in which they interact with biomedical systems to produce understandings about death.

- **Farrer, D. (2006). ‘Deathscapes’ of the Malay Martial Artist. *Social Analysis: The International Journal of Social and Cultural Practice*, 50(1), 25–50. <http://www.jstor.org/stable/23181941>**

Elaborate information on silat rituals in approaching death and dying. Contains useful references on Malay cultural knowledge of the soul, life and vitality, including what differentiates ‘bad’ and ‘noble’ death, and death acceptance. Extensive description by Malay-Muslim informants on the three stages encountered upon death, and what happens to souls of the departed.

- **Salleh, M.Y.Y and Ramli, M.A. (2019). Local Wisdom in Agony of Death among Malay-Muslim Society in Malaysia. *International Journal of Academic Research in Business and Social Sciences*. 9(9), 426–436.**

Describes death culture and customs including local wisdom in observing signs of dying. Describes the interaction between Islamic law and Malay culture and funeral management practices.

- **Djar’ie, S.M. and Prasojo Z.H. (2015) Religion, Culture and Local Wisdom in the Death Ritual of Pontianak Malay Society. *AL-ALBAB – Borneo Journal of Religious Studies*. 4(2), 201–216**

Describes death rituals and accompanying practices such as “kenduri” and “tahlil”. Discusses confluence of Malay death rituals and Islamic law of “Fardhu Kifayah” and questions the relevance of some of the rituals in accordance with Islamic law. Highlights local wisdom about “Sakratul Maut” (last moments before death) and “Husnul Khotimah” (a good end). Includes some discussion about the value of profit in death and social stratification in the Malay-Muslim cemetery.

INFLUENCE OF CULTURE AND RELIGION ON GRIEF AND BEREAVEMENT

- **Dutta, O., Tan-Ho, G., Choo, P.Y., Low X.C., Poh, H.C., Ng, C., Ganapathy, S., Ho, A. (2020).** Trauma to Transformation: Lived Experience of Bereaved Parents of Children with Chronic Life-threatening Illnesses in Singapore. *BMC Palliative Care*. 19, 1-15. <https://doi.org/10.1186/s12904-020-00555-8>

Cross-cultural commonalities were found in the narratives of Malay, Chinese and Indian family caregivers of dying children in Singapore. Acknowledgement and facilitation of rituals that are central to a family's experience and narrative of their child's "good death" can empower families and strengthen relationships leading to post-traumatic growth. Findings point to the need for greater public awareness on how friends and family members can support grieving individuals.

- **Nur Atikah, M.H., Guardia-Olmos, J. and Aho A.L. (2018).** The Use of Religion in Coping with Grief among Bereaved Malay Muslim Parents. *Mental Health, Religion and Culture*. 21(4), 395-407.

Influence of religion on bereaved parents after the death of a child and how religiosity may influence parental grief in both positive and negative ways. Some findings include how religion help parents cope better with loss, for example, religious-based motivational words, sending prayers to deceased children as ritual, gaining serenity through prayers, acceptance of fate and a way to reconnect with deceased children (giving rewards to the deceased by way of prayers). At the same time, religious faith prevents bereaved parents from discussing grief or loss because it may signal distrust in religion. Inability to discuss loss hinders the grieving process and affects spousal relationships.

MEANING OF MALAY KINSHIP AND PERSONHOOD

- **Carsten, J. (1995).** The Substance of Kinship and the Heat of the Hearth: Feeding, Personhood and Relatedness among Malays in Pulau Langkawi. *American Ethnologist* 22(2), 223-241.

Importance of kinship practices of receiving and giving nourishment as a process of becoming a person. Looks at how personhood, relatedness and sustenance are intimately connected and the way, conception, birth, living together and death are connected through the theme of substance.

MUSLIM PERSONAL LAW AND GENDER

- **Carsten, J. (1990).** Women, Men and the Long and Short Term of Inheritance in Pulau Langkawi Malaysia. *Bijdragen tot de Taal-, Land- En Volkenkunde*. 146(2), 270-288.

Role of gender and family dynamic in safeguarding inheritance for family members. While the article is about Malay-Muslims in Langkawi in the 1990s, they reference sibling hierarchies and vulnerabilities of women/daughters in accessing inheritance.

- **Noor Aisha, AR. (2019).** Muslim Personal Laws and the Accommodation of Minorities: The Need to Better Balance Individual Rights and Group Autonomy in Singapore. *German Law Journal*. 20(7), 1079-1095. DOI: 10.1017/glj.2019.71
- **Noor Aisha, AR. (2012).** Muslim Personal Law and Citizens' Rights: The Case of Singapore. *Asian Journal of Comparative Law*. 7, 1-29. DOI: 10.1017/S2194607800000697



Guest speaker from Changi General Hospital giving a talk on Advance Care Planning at *Lepaskan Sesalan (Release Your Regrets)* public engagement event 2022 at Heartbeat @Bedok

Describes the adverse implications of the administration of Muslim personal law in Singapore – specifically limiting the rights of members of the community to choose the law that is applicable to them as citizens. This accommodation results in the dominance of traditional interpretations of Muslim personal law, hindering prospect of its reform. Some aspects of the Muslim law are incongruent with change that has profoundly impacted the family, for example, gender equality in the distribution of inheritance.

CULTURAL COMPETENCE AND SOCIAL WORK

- **Ow, R. & Nur Hilyah, S. (2013). Malay Muslim Worldviews: Some Thoughts for Social Work Practice in Singapore. *Journal of Religion and Spirituality in Social Work: Social Thought*, 33(1), 73–94. <https://doi.org/10.1080/15426432.2014.874261>**

Beyond focusing on individual client factors, cultural competence should also enable social service agencies to work effectively in cross-cultural situations. Article describes importance of culturally competent social work practice to engage the Malay-Muslim community in Singapore. Provides background context to Islamic knowledge and practices and its relevance to social work practice. One significant section on health and illness, and life and death.

B. Further Reading

IMPACT OF HEALTH DISPARITIES ON MINORITY GROUPS AND END-OF-LIFE CARE:

Sheikh, A., & Dhami, S. (2020). Ethnicity and “aggressive” end-of-life care. *Canadian Medical Association Journal*, 192(11), E287. doi:10.1503/cmaj.200201

Gatrad, A. R., Brown, E., Notta, H., & Sheikh, A. (2003). Palliative care needs of minorities. *BMJ*, 327(7408), 176. doi:10.1136/bmj.327.7408.176

Roodbeen, R., Vreke, A., Boland, G., Rademakers, J., van den Muijsenbergh, M., Noordman, J., & van Dulmen, S. (2020). Communication and shared decision-making with patients with limited health literacy; helpful strategies, barriers and suggestions for improvement reported by hospital-based palliative care providers. *PLoS One*, 15(6), e0234926. doi:10.1371/journal.pone.0234926

Chin, M. H., Walters, A. E., Cook, S. C., & Huang, E. S. (2007). Interventions to Reduce Racial and Ethnic Disparities in Health Care. *Medical Care Research and Review*, 64(5_suppl), 7S–28S. doi:10.1177/1077558707305413

HEALTH DISPARITIES AND MEDICAL PATERNALISM IN SINGAPORE, AND ITS IMPACT ON THE MALAY COMMUNITY PARTICULARLY AT THE END-OF-LIFE:

Lim, R. B. T., Zheng, H., Yang, Q., Cook, A. R., Chia, K. S., & Lim, W. Y. (2013). Ethnic and gender specific life expectancies of the Singapore population, 1965 to 2009 – converging, or diverging? *BMC Public Health*, 13(1), 1012. doi:10.1186/1471-2458-13-1012

Chan, C. Q. H., Lee, K. H., & Low, L. L. (2018). A systematic review of health status, health seeking behaviour and healthcare utilisation of low socio-economic status populations in urban Singapore.

International Journal for Equity in Health, 17(1), 39. doi:10.1186/s12939-018-0751-y

Low, L. L., Wah, W., Ng, M. J., Tan, S. Y., Liu, N., & Lee, K. H. (2016). Housing as a Social Determinant of Health in Singapore and Its Association with Readmission Risk and Increased Utilization of Hospital Services. *Frontiers in public health*, 4, 109–109. doi:10.3389/fpubh.2016.00109

Tan, W. S., Bajpai, R., Low, C. K., Ho, A. H. Y., Wu, H. Y., & Car, J. (2019). Individual, clinical and system factors associated with the place of death: A linked national database study. *PLoS One*, 14(4), e0215566. doi:10.1371/journal.pone.0215566

Clement, I., Wai, A., & Chung, H. (2017). Advance care planning in an Asian country. In *Advance Care Planning in End of Life Care* (2 ed.). Oxford: Oxford University Press.

Chan, D., & Goh, L. G. (2000). The Doctor–Patient Relationship: A Survey of Attitudes and Practices of Doctors in Singapore. *Bioethics*, 14(1), 58–76. doi:10.1111/1467-8519.00180

IMPORTANCE OF DEVELOPING PARTICIPATORY AND CULTURALLY COMPETENT APPROACHES, INCLUDING THROUGH THE ARTS:

Kaur-Gill, S., Dutta, M. J., & Bashir, M. B. (2020). A Community-Based Heart Health Intervention: Culture-Centered Study of Low-Income Malays and Heart Health Practices. *Frontiers in Communication*, 5(16). doi:10.3389/fcomm.2020.00016

Betancourt JR, Green AR, Carrillo JE, Ananeh-Firempong O. Defining Cultural Competence: A Practical Framework for Addressing Racial/Ethnic Disparities in Health and Health Care. *Public Health Reports*. 2003;118(4):293–302.

Wallerstein, N. B., & Duran, B. (2006). Using Community-Based Participatory Research to Address Health Disparities. *Health Promotion Practice*, 7(3), 312–323. doi:10.1177/1524839906289376

Handtke, O., Schilgen, B., & Mösko, M. (2019). Culturally competent healthcare – A scoping review of strategies implemented in healthcare organizations and a model of culturally

competent healthcare provision. *PLoS One*, 14(7), e0219971. doi:10.1371/journal.pone.0219971

Nan, J. K. M., Pang, K. S. Y., Lam, K. K. F., Szeto, M. M. L., Sin, S. F. Y., & So, C. S. C. (2020). An expressive-arts-based life-death education program for the elderly: A qualitative study. *Death Studies*, 44(3), 131–140. doi:10.1080/07481187.2018.15274



Layang-Layang participatory activity installation at **Lepaskan Sesalan (Release Your Regrets)** public engagement event 2022 at Heartbeat @Bedok



of life & legacy

AS PART OF
Lepaskan Sesalan

**BOTH
SIDES,
NOW**
2021 – 2022

of life and legacy exhibition by community art-makers and artist, Dahlia Osman at Lepaskan Sesalan (Release Your Regrets) public engagement event 2022 at Heartbeat@Bedok

7

Annexes

A. Schedule for Community Engagement Workshops

DATES	ACTIVITIES	TIME	VENUE	ROOM	RESEARCHER PRESENT
13 Mar 2021 (Sat)	CEW #1 Age group 17 – 21	2.00pm - 5.00pm	Goodman Arts Centre	Multi-Purpose Room Blk B #03-11	Ad Maulod
14 Mar 2021 (Sun)	CEW #2 Age group 22 – 30	2.00pm - 5.00pm	Aliwal Arts Centre	Multi-Purpose Hall	Normala Manap
20 Mar 2021 (Sat)	CEW #3 Age group 31 – 39 (Male)	2.00pm - 5.00pm	Goodman Arts Centre	Multi-Purpose Room 3 Blk B #01-03	Ad Maulod
21 Mar 2021 (Sun)	CEW #4 Age group 31 – 39 (Female)	2.00pm - 5.00pm	Aliwal Arts Centre	Multi-Purpose Hall	Siti Hazirah
27 Mar 2021 (Sat)	CEW#5 First born of the family	2.00pm - 5.00pm	Goodman Arts Centre	Multi-Purpose Room 2 Blk B #03-11	Ad Maulod
28 Mar 2021 (Sun)	CEW #6 Singles who are caregivers	2.00pm - 5.00pm	Aliwal Arts Centre	Multi-Purpose Hall	Normala Manap
10 Apr 2021 (Sat)	CEW #7 Combined senior citizens	9.30am - 12.30pm	Aliwal Arts Centre	Multi-Purpose Hall	Siti Hazirah

B. Key Points on Themes, Frameworks, Archetypes and Profiles

THEMATIC LINKAGES FROM CEW (15 THEMES)

Contentious Issues: Gender
Social Expectations
Family

Peninggalan
(what is left behind)
Grieving Process (Part 1)
Grieving Process (Part 2)
Readiness

Distribution of Assets
Resistance
Planning for Death
Religion

Religion vs Tradition
Emotions
Death Taboos
Cultural Concepts

FRAMEWORKS

Organising frameworks to guide strategies and approaches when working with the Malay-Muslim community.

Individual Level Factors

1. Factors that influence degree of motivation/ resistance to dealing with end-of-life issues
2. Individual's belief systems
3. Individual's own awareness and knowledge about end-of-life and related matters
4. Individual's own skills and competencies in dealing with end-of-life and related matters
5. Opportunities which predispose end-of-life considerations

Structural/Systemic Level Factors

1. Cultural concepts pertaining to end-of-life
2. Social expectations in relation to death and dying
3. Religious injunctions and guidance
4. Endorsements by the community's leadership
5. Resource constraints among the Malay-Muslim community
6. Limitations in the Malay-Muslim community end-of-life landscape

Contentious Issues

1. Self-perception versus perceptions of others
2. Matching of end-of-life and related wishes and preferences
3. The end-of-life decision making process
4. Grieving process
5. Family's willingness and readiness to engage
6. Burdening the family

ARCHETYPES

Archetypes Encompassing Diverse End-of-Life Experiences and Needs



Caregivers



Avoidant Family Members



Close-Knit Families



Dominant Men



Disempowered Family Members



Professionals who Work in Areas that Encompass Death/Dying

Profiles on Readiness to Talk about End-of-Life Issues

1. "Wants to talk about it but don't know how/ find it difficult to"
2. "Just don't like to talk about it"
3. "It's too painful/emotional to talk about it"
4. "No capacity to talk about it"
5. "Never thought about it"

C. Thematic Overview and Suggested Programme Outcomes

INDIVIDUAL FACTORS

Level of Motivation or Resistance

- Age (not the time yet)
- Health status (terminally ill, cancer survivor, frail)
- Experience and expertise with dying process
- Past experience (personal and professional)
- Priorities/stressors in life (job, money, family)
- Socio-economic status (education, income)
- Social relationships and support
- Family dynamics
- Gender dynamics
- Complexity of each advance care planning decision (divorces, legal, money)

Belief System

- Religious beliefs
 - Religion vs tradition
- Attitudes/outlook on life and death
- Pre-existing superstitions/death taboos – (*Aib, Kubur* metaphors)

Skills and Competencies

- Communication strategies
 - Stories and what-if scenarios (from movies, radio, friends, others)
 - Messaging (legacy, prevent family fights, factual)
- Emotional readiness (anger, denial, forgiveness, acceptance)
- Resilience and coping
- Confidence (level of empowerment)
- Exposure (death, illness, nature of work eg. social worker, nurse)
- Death planning and preparation

Knowledge and Awareness of End-of-Life/ Advance Care Planning

- Misconceptions (autopsy, playing God)
- What, why, how

Opportunities

- Time for introspection/self-reflection
- Safe spaces to engage

STRUCTURAL/SYSTEMIC FACTORS

Cultural Concepts and Death Acceptance

- *Tawakkal & Redha* (faith)
- *Amalan* (deeds)
- *Taubat* (repent)
- *Aib* (shame)
- *Husnul khotimah* (beautiful closure)
- *Amanah* (what has been entrusted)
- *Fardhu kifayah* (collective duty)
- *Qada'/Qadr* (what has been ordained)
- *Seksa kubur* (torment in grave)
- *Syukur* (gratefulness)
- *Akhirat* (afterlife)
- *Neraka* (hell)

Social Expectations around Death and Dying

- Logistics of death rituals
- Stress to fulfil obligations
- Negates agency/choice in the kind of death you want
- *Usaha* (expectations of effort)

Irsyad (Islamic Opinion) on:

- Advance care planning

Fatwa

- Distribution of assets
- Organ donation

Directives, Endorsed Support or Guidance from Malay-Muslim Community (M3, mosques, religious leaders)

Resource Limitations (leadership/community)

- More immediate needs to attend to
- Lack of knowledge about end-of-life

End-of-Life Landscape

- Lack of Malay-Muslim hospices
- Lack of Malay-Muslim advance care planning facilitators
- Lack of Malay-Muslim lawyers
- Fragmented nature of accessing resources

CONTENTIOUS ISSUES

Self-Perception and Perception from Others

- Fear of negative judgement
- Gender (woman, wife)

Matching of Wishes/End-of-Life Preferences

- Between the living vs leaving
- Medical considerations vs wishes
- Cultural norms/religious obligations vs wishes

End-of-Life Decision Making Process

- Within the family
 - Sons/males/husbands; first-born; educated/knowledgeable
 - Issue of accountability (a need for shared decision making process; 'kampung decision')
 - Money means love
 - Pre-existing family conflict
- Aided by professionals (seen as person of authority)
 - Health professionals
 - Advance care planning facilitators/social workers
 - Divine intervention e.g. praying

Grieving Process

- Difficulty
- Responsibility of being the "strong person" or representative of the community
- Personal vs professional boundaries

Family's Willingness and Readiness to Engage

- Unspoken assumption that family knows what to do
- Lack of information, resources and support
- Timing and opportunities

Burdening the Family

- Cost of end-of-life interventions (life extension support)
- Cost of caregiving; effort and time
- Family needs are more important

Relationship and Trust

- With the family (including extended family)
 - Children, spouse, parents
- With the community (social support and connections)

Tension between Death Acceptance Leads to Under Planning for Death?

- Malays seem more amenable to idea of death, but when it comes to specific end-of-life preferences, is this true (contradiction)?
- Death acceptance vs prolonging life (for the leaving vs for the living)
- Professionals may engage in end-of-life work, but have not planned for own end-of-life preferences

PROGRAMME OUTCOMES

Individual Level

- Access to end-of-life-related arts interventions that are culturally competent
- Knowledge and awareness in understanding death/dying
 - Practical
 - Emotional/Social
- Develop skills and competencies to communicate about death and end-of-life preferences
- Facilitate reflection about own life trajectory and meaningful ending
- Understand emotional well-being (healing, closure, grief) in approaching death/dying

Community Level

- Inventory of community end-of-life resources that are culturally relevant
- Awareness of resources to support/facilitate end-of-life planning
 - Legal, psychosocial, medical
- Sensitise volunteers and/or advance care planning facilitators to culturally competent end-of-life approaches
- Clarify and address misconceptions surrounding death/dying and end-of-life in the Malay-Muslim community
- Demonstrate the parallels and intersections between end-of-life in the Malay-Muslim community and the wider SG end-of-life experience ie. avoid essentialising

D. The Research Team



DR AD MAULOD (LEAD ADVISOR)
Research Fellow, Duke-NUS
Medical School Centre for
Ageing Research and Education

Ad Maulod is a cultural anthropologist and Senior Research Fellow at the Centre for Ageing Research and Education, Duke-NUS Medical School, Singapore.

Ad trains and leads a team of qualitative researchers using culture-centred approaches to explore the key determinants of meaningful and healthy ageing in Singapore. Ad's research with older persons across different communities in Singapore examines the centrality of 'placemaking' in the development of age-in-place models in the community, particularly in the integration of care. Through a deeper engagement in these processes, Ad hopes to advance the development of research, policies and care-models that enhance health equity, social inclusion and community empowerment for older persons in Singapore.



NORMALA BTE MANAP
Director, Age Matters
Consultancy and Training

Normala's work in social development, with an emphasis on ageing, spans more than three decades, and she has in-depth experience of the health and age care industries at all levels. She has worked across countries and cultures at different levels of programme and policy development from building innovative start-ups and managing operations to developing frameworks for national development. Normala's work also traversed the realms of knowledge development – developing training programmes, organising workshops and conferences as well as policy dialogues and roundtables. As an age care pioneer in Singapore, she was involved in building new care models, developing frameworks for care integration and setting standards.



Hazirah is a PhD student working in the field of public health through qualitative research. She began her academic career at research centres related to palliative care and gerontology in Singapore. She specialises in working with caregivers and health care professionals on issues including decision making near the end-of-life, advance care planning and caregiving. She has designed, conducted and published studies on topics which range from tube-feeding to complex decision making for caregivers of persons with life-limiting illnesses. Hazirah is also deeply passionate about and committed to improving the quality of life and care for both patients and their caregivers.

SITI HAZIRAH BTE MOHAMAD

PhD Student in Social and Behavioural Health Sciences, Dalla Lana School of Public Health, University of Toronto



Audience member interacting with actress Suhaili Safari in *Waktu*, an interactive performance at *Lepaskan Sesalan* (Release Your Regrets) public engagement event 2022 at Heartbeat@Bedok

E. About *Both Sides, Now* and the Presenting Organisations

BOTH SIDES, NOW

Both Sides, Now is an arts-based community engagement project that aims to create safe spaces and opportunities to explore end-of-life conversations, with the hope that such conversations are normalised, and where individuals and families are supported in making informed decisions about living well, and leaving well. This project has been co-presented and produced by Drama Box and ArtsWok Collaborative since 2013, and was originally commissioned by Lien Foundation and Ang Chin Moh Foundation.

🌐 www.bothsidesnow.sg

📷📺📱 @bothsidesnowsg

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CO-PRESENTERS AND PRODUCERS

Drama Box

Founded in 1990, Drama Box is a non-profit company known for creating theatre that inspires dialogue, reflection and change. A big part of Drama Box's work is in bringing theatre to the community so that everyone can have the means to access and participate. By shining a spotlight on marginalised narratives and making space for the communal contemplation of complex issues, they seek to tell stories that provoke a deeper understanding of Singapore's culture, history and identity. Drama Box is a charity and Institution of

Public Character (IPC) registered in Singapore, supported by the National Arts Council under the Major Company Scheme for the period of April 2020 to March 2023.

🌐 www.dramabox.org

ArtsWok Collaborative

The work of ArtsWok Collaborative focuses on arts connecting communities by harnessing the power of the arts to create dialogue, invite social participation and build bridges across difference.

We work with multidisciplinary teams to design and implement innovative community-based arts programmes such as *Both Sides, Now*, a public engagement project that invites conversations about end-of-life issues, as well as *IPS Prism*, a civic-engagement project which looked at governance in Singapore. In 2015, it launched the inaugural annual youth theatre festival *M1 Peer Pleasure*, a platform for creative and open exchanges on social issues with young people through drama and dialogue. It convenes *The Greenhouse Sessions*, a field-building initiative that catalyses learning through a community of practice as well as *The Greenhouse Lab*, an action-learning programme revolving around arts-based community development. It also conducts and shares research that builds legitimacy for the arts-based community development field. Our case studies and articles can be found on our website.

We are a charity and Institution of Public Character (IPC) registered in Singapore, supported by the National Arts Council under the Major Company Scheme for the period of April 2021 to March 2024.

🌐 www.artswok.org

BOTH SIDES, NOW

2021 — 2022

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